# LETTERS TO THE EDITOR

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### Muslim families: Donating organs and asking for post mortems

EDITOR,—I thank Gatrad and Sheikh for their commentary of important Islamic ethical concepts.[1] It is has been my experience that religious and cultural factors are both important when addressing medical issues affecting Muslim families at every level.

Government campaigns encouraging organ donation have not increased organ donation in Muslim communities in the UK. A British collaborative effort led to the issuing of a fatwa (proclamations by an Islamic committee) that allowed Muslims to donate organs and carry donor cards.[2] However, evidence suggests that Muslims may be unaware of Islamic rulings on the organ donation.[3] Muslims that are unsure of the Islamic viewpoint must therefore make judgements in the context of their cultural upbringing. Muslim link workers sensitive and knowledgeable to Islamic rites concerning organ donation can be invaluable[4] in this regard. Doctors should also be encouraged to suggest to grieving Muslim families the possibility of organ donation.

The request for a post mortem examination in a Pakistani child is a difficult task. Family members may dispute the need for a post mortem examination for a number of reasons. Firstly, Islam does not allow them.[5] Secondly, a post mortem will delay burial and Muslims are keen to bury the child as soon as possible. Thirdly, because of the belief in predestination—that is, "it is Allah's will"; families feel there is no need for post mortem examination. Fourthly, families are annoyed with the fact that the child's body is going to be "interfered with":Muslims avoid the embalming or cremation of bodies, dead bodies are treated with great respect.[6]

A medical approach, sensitive to both cultural and religious factors is vital to a complete and fulfilling interaction between the family and the physician.

ASRAR RASHID
*Specialist Paediatric Registrar, Paediatric Intensive Care Unit, Birmingham Children's Hospital, UK*
*drasrar@lineone.net*

1 Gatrad AR, Sheikh A. Medical ethics and Islam: principles and practice. *Arch Dis Child* 2001;**84**:72–5.
2 Carlisle D. Life-giving Fatwa. *Nurs Times* 1995; **91**(29):14–15.
3 Randhawa G. An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrol Dial Transplant* 1998;**13**: 1949–54.
4 Sheikh A, Gatrad A. Caring for Muslim families. 106–7. Oxford: Radcliffe Medical Press.
5 Black J. Broaden your mind about death and bereavement in certain ethnic groups in Britain. *BMJ* 1987;**295**:538.
6 Rispler-Chaim V. Islamic medical ethics in the twentieth century. New York, NY: EJ Brill, 1993:28–44.

### Pediatric ethics in the Holy Quran

EDITOR,—I read with interest Gatrad and Sheikh's recent articles.[1 2] It is quite interesting to find some more references (presented as sura:verse) related to pediatric ethics in the Holy Quran.

*On organ transplantation*

"Whoever killed a human being . . .should be looked upon as though he had killed all mankind; and that whoever saved a human life should be regarded as though he had saved all mankind" (5:32). On the basis of this Quranic text, organ transplantation is encountered in many Islamic countries.

*On motherhood*

According to the Holy Quran, the mothers of infants born after in vitro fertilisation and embryo transfer are the women who give birth, not the women who give ovum: "Their mothers are those only gave birth to them" (58:2).

*On termination of pregnancy*

According to the Holy Quran, if a mother's health is treated by continuation of a pregnancy, then termination of pregnancy is allowed. "None should be charged with more than one can bear. A mother should not be allowed to suffer on account of her child, nor should a father on account of his child" (2:233; see also 2:185 and 2:195).

*On breast feeding*

According to the Holy Quran "The mothers shall give suck to their offsprings for two complete years" (2:233). However, "If they both (mother and father) decide on weaning, by mutual consent and after due consultation, there is no blame on them" (2:233). The mother who cannot and is not able to breast feed her infant, can give her baby to a wet nurse to breast feed, after mutual consent between the father and mother: "If you support financially the wet-nurse, there is no blame on you" (2:233).

The father should protect the lactating mother from any conditions which might affect breast feeding, and Islam forces fathers to provide financial support for breast feeding mothers who are divorced: "To provide food and clothing is an obligation of the father" (2:233).

MURAT YURDAKÖK
*Department of Pediatrics, Hacettepe University Faculty of Medicine, Ankara, Turkey*
*myur@gen.hun.edu.tr*

1 Gatrad AR, Sheikh, A. Muslim birth customs. *Arch Dis Child Fetal Neonatal Ed* 2001;**84**:F6–10.
2 Gatrad AR, Sheikh, A. Medical ethics and Islam: principles and practice. *Arch Dis Child* 2001;**84**:72–5.

### Medicines for children and gentamicin toxicity

EDITOR,—Recently, we changed our gentamicin dosing regimen (2.5 mg/kg 18 hourly for preterms and 2.5 mg/kg 12 hourly for term infants) as it resulted in too many low peak blood levels. Levels were taken immediately before and 1 hour after the third dose. We changed to the regimen given in Medicines for Children (MFC)[1] shown in table 1 .

However, after making this change we noticed a high number of toxic trough and peak levels. We audited this retrospectively by reviewing the blood gentamicin levels taken during the last two months of the previous regimen and the first two months of the Medicines for Children regimen. All the infants were less than 7 days old. The target levels were trough <2 mg/l, peak 5–10 mg/l. We grouped the three preterm groups given in MFC together to make comparisons easier. The results are given in table 2 .

As intended, the Medicines for Children regimen produced fewer low peaks than the previous regimen in both term and preterm infants ($p \leq 0.001$). However this was at the expense of an excess of high troughs in both term ($p=0.014$) and preterm ($p=0.004$) infants and high peaks in the preterm infants ($p=0.03$). All probabilities were calculated using Fisher's exact test.

*Table 1 Medicines for Children gentamicin dosing regimen*

| *Gestation (weeks)* | *Dose (mg/kg)* | *Frequency* | *Timing of levels** |
|---|---|---|---|
| < 28 | 4 | 36 hourly | 3rd dose |
| 28–32 | 4 | 24 hourly | 3rd dose |
| 32–38 | 4 | 18 hourly | 4th dose |
| >38 | 3.5 | 12 hourly | 4th dose |

This regimen is for infants of less than 7 days of age. *Levels were taken immediately before and 1 hour after either the third or fourth dose.

*Table 2 Comparison of gentamicin blood levels from previous regimen with those from Medicines for Children regimen*

| *Regimen* | *No of infants* | *High peaks (%)* | *Low peaks (%)* | *High troughs (%)* |
|---|---|---|---|---|
| Previous (term) | 35 | 0 | 11 (31) | 7 (20) |
| MFC (term) | 31 | 3 (9.7) | 0 | 17 (55) |
| Previous (preterm) | 21 | 0 | 10 (47) | 0 |
| MFC (preterm) | 18 | 5 (28) | 0 | 7 (39) |

Eleven high peaks or troughs have been excluded from the final figures because of the presence of renal impairment or dosage errors (3 from the previous regimen, 8 from the MFC regimen). Even with the best dosing regimen, there will always be a number of toxic levels due to impaired excretion or dosage error. In view of this, we have changed our antibiotic policy entirely and now use cefotaxime routinely in place of gentamicin. We have a low incidence of cefotaxime resistance in our unit and appreciate that this may not be an option for everyone. Occasionally we will need to use gentamicin for resistant cases and are interested in hearing from anyone who has a gentamicin regimen with which they are happy.

LOUISE GRANT
*Clinical Research Fellow*
*Department of Paediatrics,*
*Southern General Hospital,*
*1345 Govan Road,*
*Glasgow, UK*
*louise@tadams.demon.co.uk*

PETER MACDONALD
*Consultant Paediatrician*
*Department of Paediatrics,*
*Southern General Hospital*

1 RCPCH. Medicines for Children. London: RCPCH Publications Limited, 1999:245.

# BOOK REVIEWS

**On the death of a child.** Hindmarch C. (Pp 242, paperback, £17.95) Oxford: Radcliffe Press, 2000. ISBN 1 85775 445 X

Death is no longer quite the taboo subject that it has been in the past but it is still a difficult topic and one which most people meet only rarely. It is easy to feel uncertain what to do and how to help a family when a child dies. It is impossible to take away their pain and so, as Celia Hindmarch observes, "bereavement work makes everyone feel inadequate and it is always tempting to look for an expert who will do a better job". Her book sets out to help all those involved in supporting families recognise that each of us can contribute, and give us the skills to do so successfully.

Knowledge enhances confidence in a difficult situation and this is the first way in which the book helps. There is comprehensive epidemiological information about the causes of death in childhood, including stillbirth, acute and chronic illness, accidents, and suicide. The special characteristics and problems of the different situations are highlighted and brought to life by relevant case histories. Many of these focus on examples of good practice and illustrate the increased sensitivity and improvements that have taken place in the health and emergency services in recent years.

Theories of grief and mourning, especially after the death of a child, have also developed since the last edition of the book. In particular, ideas that the end of grief necessitates the severing of bonds with the deceased person have been modified. Recent research has explored the continuing bonds that parents maintain with their dead child, and how the resolution of grief depends on recognising and working with this. These recent ideas, and other models of grief, are described clearly and simply, so they can form a firm theoretical foundation for understanding the feelings and behaviours of families.

Moving from the theory to providing effective practical support for families involves sensitivity and compassion but also skills in listening and communication which can be learnt and developed. The guidelines offered in the second part of the book help us assess our own roles and suggest general principles and practical approaches for supporting families. Themes which families identify themselves and which we can respond to are the need for information, choices, control, and permission to grieve. They also remind us that "listening is more important than talking", and "being there more important than doing". Topics which provoke particular anxiety such as working directly with bereaved children, identifying situations where specialist help is needed, suicidal intentions, support for schools, and supervision are all approached thoughtfully and informatively. Finally, the book provides an overview of support services, resources and further reading.

This new edition of *On the Death of a Child* offers clear up to date information and immensely practical advice. We can all benefit from Celia Hindmarch's wisdom and experience and hopefully increase our own skills and confidence when we are faced with a child's death.

ANN GOLDMAN
*Senior Lecturer in Palliative Care,*
*Great Ormond Street Hospital,*
*London*

**Working with fathers.** Mary Ryan. (Pp 120, Paperback, £14.95) Oxford: Radcliffe Medical Press, 2000. ISBN 1857754875.

In 1995, the Department of Health published *Child Protection: Messages from Research* which summarised the findings from 20 research studies commissioned following 1987 Cleveland enquiry. Not all of the findings found their way into print. This small book, which will be principally of interest to professionals working in the field of social paediatrics, summarises what research studies have to say about fathers and the professional response to them.

The evidence from these studies, which are all based on working with children in need and children in the child protection system, shows that professionals focus mainly on mothers. This is partly because professionals do not attempt to find out about or engage with fathers and partly because fathers distance themselves. This is not a problem specific to child protection but one which also occurs in mainstream paediatric practice. The findings pose a challenge to professionals who prefer to work with mothers and make assumptions about the fathers or father figures in a family.

There are some 28 million men in the United Kingdom, of whom 22 million are potential or actual fathers. There is surprisingly little data on the sociodemography of fatherhood in the UK at the beginning of the twenty first century. Whilst most would agree that the role of the father in the family has changed, the exact way in which this change has occurred and the involvement of fathers with their children remains relatively unexplored. The book contains some revealing information about fatherhood in the UK, and the changes which have occurred over the last 40 years. It also puts into context the variety of legal relationships which can exist between fathers and their children in present day society.

There is general agreement that working with and engaging fathers benefits children. There is less agreement and certainly less research on how professionals find out more about the father's role in the family. Paediatricians routinely obtain information about the age, employment status and general health of the child's father. It might, however, be more productive and ultimately of more benefit to a child to find out more about the father's social role in the family. What is his relationship, legal or otherwise to the children? Is he resident or non-resident? What is the nature of his continuing involvement in his children's lives and what are the risks or protective factor he poses in his relationship to the children? For a busy paediatrician taking a medical history it is very often difficult to ask these questions. We still find it easier to ask about a family history of asthma rather than ask about domestic violence or if a child has ever been on the child protection register.

The book raises questions about how much training and support is given to junior staff in this area. How do doctors and nurses in training work with violent or aggressive men? How are they helped to cope with the fears they can provoke? How are professionals working with children to engage men in the long term support of their children?

The majority of parents including fathers are committed to their children. Paediatricians should start from the assumption that it is always helpful to engage with fathers. Careful assessment and better training is needed to identify those fathers where engagement is likely to be counter productive. Services to meet the specific needs of fathers are generally thin on the ground. The book contains a useful resource list and some practical examples of services, which are available specifically for fathers.

Fathers still remain the invisible parent within paediatric and social care services. This book issues some timely challenges to practitioners in the field. Too often in this area we work from a background of prejudice based rather than evidence based medicine. When it comes to fathers, the evidence is thin on the ground and there are gaps for future research.

MARY MATHER
*Consultant Community Paediatrician*

**Childhood cancer: a handbook from St Jude Children's Research Hospital.** Edited by G Steen and J Mirro. (Pp 606; hardback; £21.99). USA: Perseus Publishing, 2000. ISBN 0738202770.

This book is somewhat depressing from the point of view of a UK paediatric oncologist. Coming from such an outstanding hospital it is, as one would expect, an excellent text for all those who care for children with cancer whether they be family or professionals attempting to explain the complex, clearly and succinctly. However, it highlights the great divide between the best in Britain and the best in the USA—chronic lack of funding for resources and staff in the UK, coupled with far greater public education and involvement in America. St Jude Research Hospital has no equivalent in the UK: it brings together a vast array of talent with immense

publicly donated finances enabling it to really tackle the challenges of childhood cancer. Its contribution over the last three decades has been truly immense.

There are those who would say that the size of this text, and the depth of detail enclosed is too much for the average family to digest; for many Americans that simply is not so. It is not just the threat of litigation in America that drives the information giving; it was the same 25 years ago when I worked there and then litigation was a rarity. The thirst for knowledge is part of a genuine desire by families to understand and contribute to their child's care; if we fail in the UK to address that need, we really will go down the line of increasing complaints and legal suits. We simply need to get better at communication and to educate our population audience. The real value of the book is for all the professionals concerned to read, learn how to translate science and complex medical terms in to every day language and share it with patients and families. The era of "trust me I'm the doctor and know best" is well and truly over.

Not every chapter in this book has fully succeeded and editorial control could have been more strict for some contributions but as a whole it works well and is remarkably cheap. I believe that every UK centre ought to have several copies for staff education, let alone for loaning out to families. It is difficult not to be jealous of their talents and resources, but at least we can learn from their experience. We must improve our communication skills and learn not to patronise our patients and their families by judging what we think they can understand rather that finding out what they actually do.

TIM EDEN
*Christie Hospital NHS Trust, Manchester, UK*

**The biology of the autistic syndromes.** Gillberg C, Coleman M. (Pp330, hardback). Cambridge, UK: MacKeith Press, 2000. ISBN 1898683220.

I'm never sure if it is good sign when the receipt of a new edition of a book is accompanied by the feeling that the previous edition has only just appeared. I was surprised to find that eight years have elapsed between the second and third editions of this work. The eight years have produced a major revision with a reduction in the number of chapters (most completely rewritten) and evidence of self restraint in a mere 4% increase in the number of pages.

One addition is that of a preface devoted to a robust defence of the concept of autistic syndromes rather than that of an autistic spectrum. Readers will have to judge for themselves but this reviewer was not convinced by the arguments presented. The presence of a table in chapter 2 devoted to the autistic spectrum and the title of chapter 8 (The epidemiology of autism and its spectrum disorders) suggests that the issue may not be so clearcut.

Semantics aside, there is much to recommend this book. There is a clear guide to the classification of autistic syndromes and diagnostic criteria with advice on practical application. There is a chapter about diagnosis in infancy including a fascinating list of physical signs associated with autism (this reviewer was previously unaware of the possible significance of partial syndactyly of 2nd and 3rd toes). There is less discussion, however, of the benefits of early diagnosis or of the implications of error in making such a diagnosis. The chapter on the clinical course of autism emphasises the dynamic nature of the condition and the real possibility of changes during adolescence. The next chapter logically deals with adults with autism although emphasising our lack of knowledge of this subject with its brevity.

The new edition has a chapter entitled "Double syndromes" replacing a group of chapters in the previous edition under the heading of "Disease entities that have a subgroup of patients with autistic symptoms". I am not yet convinced that it is helpful to describe many patients with some autistic features associated with a clear primary diagnosis as having two separate disease entities.

The controversy over the possible links with MMR immunisation is discussed briefly but in a balanced fashion with pointers to emerging research into the apparent link between autism and some gastrointestinal disorders.

Discussion of possible therapies, medical and non-medical, is fairly brief (perhaps appropriately so in a text dealing with the biology of autism) but provides a good summary of current approaches. This book provides a good overview of the subject of autism (whether syndromes or spectrum) and will be of use to all paediatricians dealing with children with the diagnosis. This reviewer will be interested to see if the interval until the next edition passes so quickly . . ..

MARK HUNTER
*Consultant in Community Paediatrics, Banbury, UK*

**Hirschsprung's disease and allied disorders. 2nd edition.** Edited by Holschneider AM, Puri P. (Pp 503, hardback, $125.00). Australia: Harwood Academic Publishers, 2000. ISBN 90 5702 263 X.

In 1887, Harald Hirschsprung published the first detailed description of congenital megacolon, but it was not until 1948 that the true nature of the disease was defined. The discoveries at that time included the finding of aganglionosis in the rectum, the demonstration that peristaltic activity in the colon was propagated only as far as the narrowed aganglionic segment of bowel, and the relief of obstructive symptoms by rectosigmoidectomy. The key histological feature in Hirschsprung's disease is the absence of ganglion cells, which not only affects cholinergic neurons but also non-adrenergic, non-cholinergic neurons, which use nitric oxide as their chemical messenger. Aganglionosis is restricted to the rectum and sigmoid colon in 75% of patients, extends more proximally in 15–20%, and affects the entire colon and a variable length of ileum in 8%. Rarely, ganglion cells are absent from most of the gastrointestinal tract.

This multiauthor text on Hirschsprung's disease contains contributions from an array of world experts. The editors, Alexander Holschneider and Prem Puri, are recognised authorities and they have compiled an invaluable reference source for paediatric surgeons, paediatricians, scientists, and others. The book progresses from discussions of the physiology and pathology of gut innervation, through clinical aspects of Hirschsprung's disease, to surgical techniques and their results and complications, and finally to long term outcomes. The style of the book is similar to the first edition published in 1982. Operative line diagrams and sketches are generally of good quality but all histology and operative photographs are black and white. There is inevitably some repetition of information, particularly in relation to results and complications, but this allows the reader to consider data from different perspectives. Clinical features of Hirschsprung's disease are only briefly discussed and there is little comment on the different methods of rectal biopsy and their complications. However, such deficiencies are minor and more than compensated by outstanding chapters on functional anatomy of the enteric nervous system (Michael Gershon), colonic motor function (James Christensen), and the pathophysiology of Hirschsprung's disease (Alois Scharli).

Recent developments are discussed, including the obscure relationship between Hirschsprung's disease and intestinal neuronal dysplasia and innovations in surgical practice such as primary pull-through and laparoscopic techniques. Long term complications, principally constipation, enterocolitis, and faecal incontinence, are also reviewed. The latter has a highly variable incidence between different surgical units and is influenced by many factors including the timing and type of pull-through surgery, the extent of aganglionosis, methods of assessment and the age at which they are applied, and whether patients are evaluated with or without dietary modifications, oral medication, enemas and suppositories. Continence may improve during adolescence but techniques such as the antegrade continence enema offer hope for those with intractable soiling.

This book also reviews recent breakthroughs in the molecular genetics of Hirschsprung's disease. At least three susceptibility genes have been identified: the RET proto-oncogene (chromosome 10), the endothelin-B receptor gene (chromosome 13) and the endothelin-3 gene (chromosome 20). It is estimated that RET mutations account for 50% of familial and 15–20% of sporadic cases of Hirschsprung's disease.

For anyone interested in Hirschsprung's disease, this book provides the most comprehensive and authoritative source available.

MARK D STRINGER
*Consultant Paediatric Surgeon*
*Leeds Teaching Hospitals NHS Trust, Leeds, UK*