Care of Patients Towards End of Life: Quest for the National Training and Guidelines

Sir,

I read with interest the editorial by Robyna Irshad Khan in the December issue. The author has very eloquently outlined some of the ethical issues regarding the end of life care in Pakistan. The issues of confidentiality, mental capacity, advance directives and patient’s autonomy of decision-making have been highlighted. The problems of inadequate teaching, training and practice of advanced communication skills, lack of facilities and concept of palliative care and availability of simple resources like supply of necessary analgesic medicine have also been mentioned.

It is important to understand that “palliative care” is the active care of patients whose disease is not responsive to curative treatment. It may be delivered by any healthcare professional. “Specialist palliative care” is the palliative care delivered by those with specialist training in palliative care, for example, like McMillan nurses in United Kingdom, usually for more difficult and complex cases. Persistent vegetative state is an irreversible condition resulting from brain damage, characterized by lack of consciousness, thought, and feeling, although some reflex activities, such as breathing continue. However, “terminal care” is the care of a person in the last days or weeks before they die. Understanding these precepts allows end-of-life care to be planned in an effective manner.

The guidance issued by the General Medical Council of UK, published in 2010, outlines the principles of good medical practice, the responsibilities and duties of a doctor in providing treatment and care towards the end of life. This guidance is for patients who are approaching the end of life when they are likely to die within the next 12 months. The current “Code of Ethics” of practice for medical and dental practitioners of Pakistan Medical and Dental Council states that “End-of-Life care requires control of pain and other symptoms, decisions on the use of life-sustaining treatment, and support of dying patients and their families. Futile treatment need neither be offered to patients nor be provided if demanded. A treatment is qualitatively futile if it merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care or when physicians conclude, either through personal experience, experiences shared with colleagues, or consideration of reported empiric data that a medical treatment has been useless. The physician is not compelled to accede to demands by patients or their families for treatment thought to be inappropriate by healthcare providers.”

Physicians can only provide an account of empirically observed physiological states but cannot, on those terms alone, answer the onset of death on religious - ethical basis. The religious and scientific definitions of death are not the same. It creates a challenge for the family members and the healthcare professionals to make a life-death decision. The interpretation of the scientific information perceived and processed by the individual patients with the terminally ill medical condition and their families is very often strongly influenced by the cultural, religious, moral and socio-economic status and values.

The question requires discussion as who has got the authority to restrain life-sustaining treatments. In a country like Pakistan, where majority of population is Muslim, there is a need to develop a consensus as where to draw a line between personal values and beliefs of people and a more objective medical analysis made by healthcare providers.

A doctor is obliged to show respect for human life, to protect the health of patients, to treat patient with respect and dignity and to make the care of their patients their first concern. These are the basic ethical principles apply to all the doctors irrespective of the country where they are working. However, doctors in any circumstances should not allow their personal belief to overpower the agreed guidelines and regulations. It is important to understand the distinction between “active” and “passive” euthanasia. There is an important moral question for the healthcare professionals in foregoing life sustaining treatment: would such a decision can be regarded as a form of killing, and if so, whether it is “assisted suicide” or “homicide”.

PMDC needs to provide explicit up-to-date guidance to doctors to provide care towards the end of life in the light of local and current Islamic biomedical ethical issues. Also, this is the time for the College of Physicians and Surgeons Pakistan to realize the need, consider to facilitate research, develop special faculty of Palliative care, generate discussion and organize more courses of advance communication skills focusing such issues.

REFERENCES

Sir,

Subcutaneous fat necrosis (SFN) is a rare disorder occurring in newborns that is usually self-remitting and non-recurring. Worldwide only 200 cases have been reported till now. It is a transient, benign process of unknown etiology in full-term or posterm neonates who experienced a perinatal distress.1 SFN is an important entity and should be considered under differential diagnosis of cellulitis and sclerema neonatorum (SN).2,3 In these conditions, patient is septic and needs prompt diagnosis and treatment. Keeping the possibility of SFN in every neonate who presents with such picture, makes it possible to avoid overtreatment, unnecessary evaluation, and stress of parents and physicians. Hypercalcaemia may be a potentially life-threatening complication of this otherwise self-healing process. It may take 6 months to present clinically. So after diagnosing SFN, patient should be evaluated for hypercalcaemia for at least 6 months.4,5

A 3-kg male newborn was delivered at term by an emergency caesarean section due to decrease fetal movements. The mother was gravida 2, para 1. Antenatal history revealed a normal course with no risk factors. Apgar score was 6 and 8 at 1 and 5 minutes respectively. He was shifted to the neonatal intensive care unit for 24 hours for observation for mild distress. Oxygen was given for few hours; he recovered and was started on breastfeeding. He remained well and was discharged in stable condition on day 3 of life. The neonate presented on 7th day of life with firm, symmetrical non-tender violaceous subcutaneous nodules marked on cheeks, forearms, arms, and back. There was no history of trauma. The baby was otherwise asymptomatic with normal vital signs and was feeding well. The lesions were not warm but minimally indurated. There was no lymphadenopathy, hepatosplenomegaly or oedema. A septic workup was negative. Routine laboratory investigations were normal including C-reactive protein (1.1 mg/dl) and calcium (8 mg/dl). An ultrasound of lesions showed a well-defined isoechoic mass in the regions of the subcutaneous fat, but there was no fluid. The parents were reassured and asked for monthly follow-up and to return earlier if there was any deterioration. Monthly serum calcium level was done, which remained within normal limits. At 6 months follow-up, baby was symptom-free and his lesions were resolving without any complications including hypercalcaemia. Renal scan showed no evidence of nephrocalcinosis. Serum calcium level at 6 months of age was 9.9 mg/dl (normal 8.5 – 10.5 mg/dl) and ionized calcium was 4.95 mg/dl both values being within normal limits.

SFN is a benign, self-resolving condition that does not require any specific treatment. It needs to be differen-
tiated from sclerema neonatorum and cellulitis.

REFERENCES


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Knowledge, Attitude and Practice Regarding Prostate Specific Antigen (PSA) and Prostate Biopsy

Sir,

Prostate cancer is the most common malignancy especially involving elderly population and second
leading cause of cancer related deaths among men.\textsuperscript{1} Screening for prostate cancer is still a controversial topic and recently much debated in contemporary literature.\textsuperscript{2,3} The methods of screening are digital rectal examination and serum prostate specific antigen (PSA) test. In case of abnormal digital rectal examination and/or elevated PSA, a prostate biopsy is recommended to confirm the diagnosis. However, the practices are not standardized and there is a need to optimize these practices in order to improve the diagnostic yield and to minimize the associated morbidity.\textsuperscript{4} Standardized practice in care of oncological patients is the key to successful outcome. National consensus on diagnostic, screening and management strategies is needed to develop standardized practice pattern.

There is considerable debate about the screening of prostate cancer, therefore, it is imperative for a urologist to be fully aware of the disease, diagnosis and proper management, especially with the lack of specialist centres in a developing country like Pakistan.

Pakistan association of urological surgeons (PAUS) is the only registered organization of country’s urologists from both public and private sectors engaged in community based and academic practices. This association was founded in 1997 with the aim to develop the growing field of urology in this country, bringing together the ideas and experiences of these specialists on a single forum, transforming this association into a scientific body. Currently, this association has around 250 members and 11 chapters in the major cities of the country.\textsuperscript{5}

In this study, we surveyed a group of urologists to identify their pattern of knowledge, the attitude and practices regarding the use of PSA (prostate specific antigen) and prostate biopsy using a questionnaire. This cross-sectional study was conducted at the monthly meeting of Pakistan Association of Urological Surgeons (PAUS), Karachi, Chapter in December 2010 held at the Aga Khan University. The questionnaire comprised of 12 questions, 5 on knowledge, 3 on attitude and 4 on practice, based upon the European Association of Urology (EAU) and American Urology Association (AUA) prostate cancer guidelines regarding PSA and prostate biopsy. These included questions regarding various aspects of PSA dynamics, indications for PSA parameters and prostate biopsy and practices like use of analgesics and antibiotic prophylaxis. The responses were gathered in the form of a single best option and correct responses and overall scores were grouped into excellent (> 80%), good (60 – 79%), average (40 – 59%), poor (20 – 39%) and very poor (< 20%) for each question.

Total number of eligible responders was 27, with 12 (45%) consultants and 15 (55%) residents (response rate 69%). The overall responses were mixed and variable between one area to another ranging from very poor to excellent (Table I). The correct response rate varied from 11 – 70% in all the aspects of knowledge, attitude and practice. The correct response rate was better in all three domains by consultants as compared to residents. Most of the practices were against the recommended guidelines. This fact is alarming because misinterpreting the information and non-uniformity in the practices regarding PSA and prostate biopsy can have adverse consequences for the patients, increasing the complications and morbidity.

This cross-sectional study helped us to identify many inaccuracies in various aspects of prostate cancer screening and diagnosis. The noticeable divergence from recommendations guideline also identifies that our consultants and residents do not read them.

In view of these conclusions, more efforts are needed to direct a guideline based urological practice, offering improved standard of care for a third world population.

### Table I: Comparison of overall correct responses in domains of knowledge, attitude and practice.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Correct response rate</th>
<th>Residents (%)</th>
<th>Consultants (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1. The median (normal*) value of PSA in ng/ml is:</td>
<td>11 7 17</td>
<td>0.41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Which of the following do you consider to be the most important marker for prostate biopsy?</td>
<td>30 20 42</td>
<td>0.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Do you think that mid-life single PSA in an asymptomatic patient has prognostic significance?</td>
<td>15 20 8</td>
<td>0.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Which of the following is an indication for prostate biopsy?</td>
<td>44 27 66</td>
<td>0.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. What is the risk of UTI / sepsis following prostate biopsy?</td>
<td>30 7 58</td>
<td>0.01</td>
<td></td>
<td></td>
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<tr>
<td>Attitude</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. A patient presenting with a single raised PSA &gt;10 ng/dl warrants biopsy?</td>
<td>52 60 50</td>
<td>0.24</td>
<td></td>
<td></td>
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<tr>
<td>7. What is your preference for prophylaxis regarding biopsy?</td>
<td>19 20 17</td>
<td>0.61</td>
<td></td>
<td></td>
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<tr>
<td>8. Would you consider doing biopsy on low dose (75 – 81 mg) Aspirin?</td>
<td>30 40 17</td>
<td>0.19</td>
<td></td>
<td></td>
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<tr>
<td>Practices</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>9. How many cores in a prostate biopsy do you think are adequate for you to conclude a diagnosis of Ca prostate?</td>
<td>37 33 42</td>
<td>0.48</td>
<td></td>
<td></td>
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<tr>
<td>10. What prompts you a repeat biopsy?</td>
<td>70 67 75</td>
<td>0.48</td>
<td></td>
<td></td>
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<tr>
<td>11. Saturation prostate biopsy should be performed in those with following:</td>
<td>33 7 67 &lt; 0.01</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. What analgesia do you prefer for prostate biopsy?</td>
<td>18 20 17</td>
<td>0.61</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Letters to the editor

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REFERENCES


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