Editorial

Patient centred approach in endocrinology: From introspection to action

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It was a hot sultry August evening. The young endocrinologist was visibly tired after a full day's work. The day had been, by and large, a demanding but monotonous one, with an endless number of diabetic patients streaming in for consultation. However, the monotony ended abruptly as the next patient was ushered in. The patient was a cute baby girl whose infirmity belonged to a completely different realm of endocrinology.

He was a young confident endocrinologist who had very recently completed his fellowship at the most prestigious institute in the country. He thought he knew everything that was worthy of being known! The presence of the baby stirred up his "endocrine brain" to make forays into the baby's history, and he systematically reached a "rare" diagnosis (of congenital adrenal hyperplasia (CAH)). His treatment plan revolved around informing the parents of their baby's diagnosis, of the nature of the disease, and of course the need for lifelong glucocorticoid replacement to keep their daughter alive. It also included informing the parents of what would happen if the baby was to be deprived of "steroid." With this, he thought he had done a great job.

The next few weeks were passed in anticipatory concern. Indeed, feedback came in the form of a telephonic query from the mother who wanted to know the gender of her child. The young endocrinologist asserted that the baby was a "girl" and categorically discouraged any further discussion in this aspect.

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The rest of the story is short and tragic. The parents totally disagreed with the doctor. Their dilemma, given that baby had ambiguous genitalia, was pretty obvious even during the outdoor consultation. The fact that they belonged to a society where gender rates are heavily skewed against females, also contributed to their misery. The child was no longer brought back to the endocrinologist for consultation, and left to the mercy of a local "*I can heal them all*" practitioner of alternative medicine. She finally succumbed to a severe hypoadrenal crisis following a bout of diarrhea. The battle for diagnosis was won, but the war for survival was lost!

However pragmatic the young endocrinologist's view would seem, it completely ignored the psychological build-up of the parents and the society they belonged to. The tragedy could certainly have been averted if the parents had been taken into confidence, made equal partners in decision making, and allowed a patient-centric approach to management. In later years, this realization would come back repeatedly to haunt the endocrinologist, along with the remembrances of what his teacher had taught him repeatedly, in defiance to standard western textbook teaching: the choice of gender of rearing should be discussed with, and left to, the parents (Dr A.C. Ammini).

Patient-centered professionalism (PCP) has been acknowledged to be an integral part of good medical, nursing and pharmacy practice.[1] Specifically, the advantages of patient-centered approach have been highlighted in the context of chronic disease management.[2] Within the purview of endocrinology and metabolism, diabetes management has long been influenced by the principles of patient-centric care.[3]

In fact, patient centered approach now occupies centre-stage in the latest diabetes management guidelines.[4] Other aspects of endocrine care, are however, seem not to have felt the effect of patient-centered strategies in their practice.[5]

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PCP has been defined in various manners. Doctors are expected by parents to exhibit competence, respect, honesty, and have the ability to communicate with them. It should provide patients with sufficient autonomy, treat the patients and public as partners, and be focused on values and standards agreed to by the public and the medical profession. The concept of PCP should be integrated in medical education, and be guaranteed through licensing, certification, and awarding employment contracts.[1]

The attributes of good diabetic care, or rather, good endocrine care, are captured in the acronym "CARES" [Box 1], which can be used to describe the features of PCP.[6]

The term PCP also encompasses the concept of shared discussion making (SDM). How does an endocrinologist decide whether SDM is appropriate or not? And how does one ensure that the patient is an equal, and avid participant in the decision-making process? The key to this is patient empowerment.[5] The patient empowerment has been defined in various ways. An earlier editorial in this journal discusses ways in which endocrine patients can be empowered to improve therapeutic outcomes.[5]

SDM is acceptable insofar as it does not lead to a potentially life threatening or organ destabilizing situation. For example, for a patient with diabetic ketoacidosis to insist on oral anti-diabetic drug (OAD) cannot be accepted under the disguise of SDM. Similarly, if a surgical procedure is absolutely indicated for diabetic foot, it has to be performed at all cost. On the other hand, a patient with so-called secondary OAD failure, and no immediate complications may decide to choose triple oral therapy over insulin. The examples sited above underscores the acceptance of patient-centric approach on the part of endocrinologist in diabetes care. At the same time, they bring to light the almost near-total lack of such a professional approach in other sub-specialties of endocrinology. The following examples are food for thought, and of course, stimulus for introspection.

Patients with panhypopituitarism presenting to an average Indian endocrine consultant certainly get replacement for adrenal steroid and thyroxine, but are less likely to be offered sex steroid replacement, and most likely would never be even informed about growth hormone replacement, albeit in the pretext of financial constraint (rather than medical reasons). The same is true while planning treatment in acromegaly, which can be treated both medically and surgically: patients are usually not offered the option of pan-hormonal replacement.

In Graves' disease, multiple therapeutic options are available. A PCP, using SDM after adequate patient empowerment, helps find the most suitable method of treatment for a particular patient. Yet, in practice, we usually tend to prescribe the modality of therapy that we feel is best, without involving the patient in decision making. Another interesting example in clinical thyroidology is using customized treatment regimes (atypical timing and frequency) for thyroxine replacement/supplement. This gives us ample scope to meet patients' needs and concerns and eventually increase their compliance.

In diseases such as rickets, osteomalacia, and osteoporosis, multiple approved therapies are now available. There is conflicting data on the outcome of even a single modality in different trials. Rarely, if at all, does the endocrinologist discuss in details about the lack of consistent data and empower the patient to choose the right modality, such as choosing between yearly injection of zolendronic acid and weekly tablet of alendronate.

Handling of gonadal and sexual diseases also requires a strong patient centered approach.[7] Patients should be definitely allowed to control decisions related to their reproductive and sexual health, provided these decisions are not potentially harmful. Adrenal diseases represent a unique challenge for patient centered endocrinology as exemplified in the story in the initial part of this article.

While anecdotal examples such as above puts emphasis on adapting to patient centered management in endocrine disorders, the question remains: how do we usher in such a paradigm shift in the current standard of care. Some suggestions are put forward in Box 2.

The endocrine community at large should debate extensively about how far one should go in involving patients in decisions that impact their lives, and about how much can "scientific accuracy" be sacrificed for "social appropriateness." One

Box 1: Components of Patient-Centered Professionalism

C compassionate competence
A authentic accessibility
R reciprocal respect
E expressive empathy
S straightforward simplicity

Box 2: The "I see" Approach to Bring in a Paradigm Shift towards PCP in Endocrine Practice

Improve communication skills of the doctors
Sensitize the endocrine fellows to the importance PCP, its scope, limitations, and the caveats for its successful implementation
Enhance patient education and counseling in all endocrine disciplines
Encourage SDM

PCP = patient-centered professionalism, SDM = shared decision making

needs to introspect as to what is paramount in endocrine practice: patient satisfaction or physician pride.

Careful examinations of available evidence tell us that we do not know, with certainty, about much that we practice in endocrinology. Does growth hormone therapy increase final height in children with idiopathic short stature? For how long should we treat microprolactinomas? To what target of TSH should we treat hypothyroidism in asymptomatic patients? Which is the ideal regime for vitamin D replacement? Do all patients with diabetes need to achieve a fixed target HbA1c, or can we have "flexitargets"? Who decides gender of rearing of an intersex child? Which patient is an appropriate candidate for hormone replacement therapy after menopause?

Perhaps our patients have the answer. If only we could listen to them!

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