

Issues of Autonomy and Truth Telling in Pakistani Culture

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Healthcare providers in Pakistan face unique cultural and social circumstances when dealing with patients and their families. In emotionally charged situations, where physicians need to convey information about a diagnosis with unfavorable outcome/prognosis, family members are often taken into confidence before communicating with the patients. It is not an uncommon scenario in Pakistan that consent forms of even adult patients are signed off by their male relatives like a husband, father, brother and even a son at times. It is understandable and acceptable in case of patients who lack capacity to make their independent decisions like children, comatose patients, neurologically or psychologically dependent patients. The practice, however, extends to adolescents and adults with capacity. Sharing medical information with family members and allowing them to make decisions, whether major or minor, poses significant threat not only to moral principle of respect for autonomy but also confidentiality and veracity. Because in following family wishes to keep the information from the patient, healthcare providers not only break the patient-provider trust but also often lie or make false claims about treatment or prognosis. This practice is also leading to a generation of healthcare providers with not only lesser physical and emotional engagement with their patients but also lack of responsibility and little reliance on good communication skills required to share such information. Respect for autonomy is an ethical principle with roots embedded in common morality. In healthcare context, the right of a patient to accept or refuse a medical treatment is based on this principle of respect for autonomy, described as the “right to self-determination” by Beauchamp and Childress.¹ Respect for autonomy doesn’t only mean that people make independent choices but also to respect their independent, autonomous choices. Some individuals lack the capacity to make rational decisions. A rational choice is a demonstration of autonomy, according to Immanuel Kant.² Hence, caregivers of children and adults with brain injury and mental health problems are often universally accepted as their decision-makers. Individual autonomy has been compared, by ethicists, to relational autonomy and practical implications in clinical settings have been discussed and debated.³ Individual’s decisions are exceptionally influenced by the social context. The ethic of care and responsibility, therefore, guides healthcare providers to take into account the concept of autonomy that promotes respect of individual decision-making in close context of social and cultural milieu. An aspect of respect for persons, other than autonomy, is a moral concept of honest disclosure.⁴ Traditionally, lying to people is considered morally wrong and disrespectful. The argument against this is based on the consequence i.e. if the act of lying produces a good result, it is acceptable to lie. However, the proponents of honest disclosure hold that lie is prima facie wrong, irrespective of the consequence. This said, most of the moral systems as well as professional codes of conduct consider honesty as a trait to be exhibited and practiced by physicians. So does Pakistan Medical and Dental Council, in the Code of Ethics (Part IV; 15.1 & 21.5a).⁵ Similarly, physicians are responsible for keeping the confidentiality of the medical information. Trust of a patient is earned by giving them respect. Pakistan has a very unique social, cultural and religious position as compared to the rest of the world in general and the western countries in particular. A variety of social and religious beliefs dominate our moral values and social norms. The society is predominantly patriarchal where male members of the family hold authority to make all decisions. It would be, therefore, unfair to keep them out of picture while making critical decisions about health of a family member. The strong sense of community living also inculcates the traits of taking care

of each other, particularly the physically and economically weaker members of the society. Family, therefore, is an important unit of our society and comprises of extended family members as well, like grandparents, uncles and aunts etc. This communal living, therefore, makes involvement of family members in decision making, no matter how small or big, very acceptable. Hence, family members play a crucial role in healthcare decisions of patients as well. The physical, emotional and financial interdependence has a major influence in health related decisions in Pakistan. It has been fairly emphasized to involve family members as stakeholders in the process of decision making in healthcare. The importance of family involvement in decision-making in healthcare cannot be challenged. The value of cultural sensitivity and humility has been a buzz word in medicine, worldwide. As healthcare providers we must respect the values and wishes of the patients, their families and their culture.⁶ In wake of this, the healthcare providers in Pakistan are justified in their practice of sharing information with family members of the patients. The most important thing to remember, however, is that the central character of the story remains the patient, always. Irrespective of the patient's level of dependence on the family members, the wellbeing and best interests of the patient must remain the priority. The family, physician and patient triad is impossible without the patient. Patient's wishes, present or past (in case of comatose patient etc.), must remain significant in making health related future plans. A more reasonable way should be to ask the patients who they want to be with when the detailed information is being shared by healthcare providers and who they think should be discussing further details with the providers. Respect for social and cultural norms is justified but physicians cannot let go of their responsibility towards patients. In fact, they bear the burden of finding out wishes of their patients even when not explicit. Human dignity is a human right, as per Universal Declaration of Human Rights.⁷ The virtues of healthcare providers and particularly physicians include honesty, dependability, prudence, humility and fidelity. Physicians hold a very high level of respect and trust in Pakistani community and their patients deserve a lot more than a false hope. Contextual factors hold grave importance in decision-making and disclosure of information in healthcare. The common practice in Pakistan by healthcare providers is paternalistic. It is socially acceptable but raises some ethical issues of respect for person, confidentiality and veracity. The onus of making a decision of how, what and to whom the information is disclosed remains with the physicians. Therefore, good communication skills and sense of responsibility towards patients are required along with conscience. It is easier to give clinical information to family members, who in their purest intentions believe that the patient will be better off without knowing the details. However, building trust with patients and their families is crucial and desirable to respect the patient as a human being who is in a very vulnerable situation. Taking families onboard is as important as discussing with the patients what and how much they would like to know. It takes time and effort. Professional and ethical conduct requires patience and humility, trust and kindness, and compassion and thoughtfulness.

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