

Framework for Shared Decision-Making and Care Ethics in a Resource-Constrained Environment

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A SILENT FAREWELL

They named him Adam. Their miracle. But, with a broken heart and an incomplete brain, the doctors said he had little chance to live a normal life. They advised them to let him go, without the pain of surgery • But how could they? He was their firstborn. They wanted to give him a chance, to fight for his life. They wanted to pray for a miracle, to hope for a cure • They came from a conservative community. Life was sacred. They couldn't talk to their relatives without being misunderstood. They wanted him to have a cardiac surgery, even if it was risky and costly • Perhaps they can't. They were poor. They were immigrants. They had no voice in the society. They couldn't talk to the doctors, they seemed busy. They couldn't talk to each other, they blamed themselves for their son's condition • The doctors tried. They felt equally frustrated. The hospital was crowded and noisy. They couldn't devote enough attention to them. They gave them smiles and nods, and hoped they would feel them • But they did not • They felt alone and lost. They did not know who to trust or what to do. They did not know how to cope or how to hope • They wished for someone who could bridge the gap between medicine and religion, between science and spirituality, between facts and values, between death and love • They wished for someone who could listen to their stories and understand their emotions • They wished for someone who could respect their culture and honour their dignity • They wished for someone who could empower their perspective and facilitate their autonomy • They wished for someone who could offer them compassion, that was inclusive and individualised • They wished for someone who could help them find meaning and purpose in their suffering • They wished for someone who could help them say goodbye • But they never found that someone.

FRAMEWORK FOR BEDSIDE ROUNDS

(1) ESTABLISHING AN APPROPRIATE ENVIRONMENT

- Acknowledge the impact of the hospital's rush and lack of emotional space
- Address and remove social hierarchical norms
- Allocate protected time

(2) CONDUCTING THOROUGH PSYCHOSOCIAL ASSESSMENTS

- Assess psychosocial wellbeing (economic, social, mental, emotional, and cultural determinants of health)
- Consider the patient's and family's perspective and preferences, using child-friendly methods and tools, where applicable
- Emphasise the importance of shared-decision making

(4) EMPOWERING PATIENTS AND FAMILIES

- Ensure access to understandable information about patient's condition, treatment options, and potential outcomes
- Implement decision support tools, such as decision aids and plain-language materials
- Support the child's right to participate in decision-making, and respect the family's role and values

(3) NURTURING COMPASSION

- Take time to sit and listen
- Foster a caring relationship, encouraging dialogue and deliberation, rather than persuasion
- Encourage patients and families to ask questions and voice their concerns, providing question prompt lists to facilitate discussions, where needed

(5) BUILDING TRUST

- Recognise the uncertainty and complexity of decision-making and do not impose a single or ideal solution.
- Look into patient's and family's unspoken desires and individual aspirations.
- Be flexible and be willing to adapt to changing circumstances.

(6) CREATING INDIVIDUALISED CARE PLANS

- Reassess and update care plans based on the evolving unique needs and wishes of the child and family
- Respects the diversity and plurality of values and beliefs among different cultures and religions and seeks to accommodate them in the care plan

BRIDGING CULTURAL DIVIDES IN PALLIATIVE CARE



FRAMEWORK FOR SUPPORT SYSTEMS

(2) CULTURAL SENSITIVITY

- Cultivate a sense of care and respect for the diversity of cultural beliefs, practices, and values among patients, families, and healthcare providers
- Provide specialised training in cultural competence that recognise and mitigates social hierarchical behaviours.

(1) MITIGATE RESOURCE CONSTRAINTS

- Advocate for dedicated resources and additional time for discussions
- Collaborate with administrators and policymakers to ensure adequate resources and infrastructure for the expansion of care services.

(3) CULTIVATION OF A COLLABORATIVE ECOSYSTEM

- Foster collaboration among healthcare providers, families, and religious and community leaders to create a support network
- Engage with non-governmental organisations to play an active role in advocating, educating, and supporting initiatives.
- Involve patient advocacy groups in promoting the value of shared decision-making and advocating for its integration into practices.

(4) CONTINUAL IMPROVEMENT

- Establish feedback mechanisms for stakeholders to share their experiences on shared decision-making and suggest improvements.
- Continuously assess the impact of its initiatives on patient and family satisfaction and well-being outcomes.
- Encourage research initiatives to understand the cultural, social, and ethical aspects of care in a multicultural setting and inform policy development, clinical practices, and education