Shared Decision Making and Medico-legal aspects: Delivering High-Quality Cancer Care in India

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Introduction

➢ Considering the life-threatening course of cancer and its emotional impact, its often difficult for patients to make decisions for their care

➢ Patient-centered communication is gaining importance with the evolution of modern interdisciplinary cancer care and the emergence of personalized medicine.

➢ Patients have expressed desire to have information regarding medical condition and available treatment options

➢ Western world research has demonstrated that having communication, shared understanding and trust between patients and health care providers are paramount to the success of treatment.

  • Shared decision making (SDM) is an evolving practice in medical care and a key component to healthcare policies

➢ Its increasingly adopted by physicians, patients, and policy makers

➢ SDM includes collective efforts of all to build consensus for the preferred treatment
Objectives

➢ SDM has been gaining trends in western world
  o In US, the Patient Protection and Affordable Care Act supports the patient-centered medical home models of primary care
  o In UK, the National Health Services (NHS) has emphasized upon the importance of SDM in healthcare and access to patient decision making aids

➢ We conducted review of literature with the objective to:
  o Understand the role of SDM in Indian clinical scenario
  o Identify the gaps as compared to the western world
  o Suggest future actions to bridge the gaps
Materials & Methods

- Literature search using key words was performed in Pubmed & Google Scholar (2002-2017)
  - Key words: Shared decision making, Cancer care, Patient centered care
  - ~400 articles were retrieved. Articles were further shortlisted for Patient engagement, Decision making aids, patient empowerment
  - ~100 articles were further shortlisted
    - Filtered for duplicity of statement
  - 38 articles shortlisted
    - Western & Indian world data was compared, Gaps were identified
Results (1/2)

➢ We observed that there is paucity of information published by Indian authors on SDM as compared to western world.

➢ Western world data demonstrates sharing of information by both patient and physician, and collective efforts of the two to build consensus for preferred treatment
  o when offered choices, patients were more active in decision making
  o patients who are well-informed about prognosis and treatment options, including benefits, harms and side effects, are more likely to adhere to treatments
  o desire for participation has been found to vary according to age, educational status, disease severity and cultural background.
  o When patient involvement does not occur, it may be due to a perceived lack of time or may be because the provider does not have the skills to involve patients in decision making.

➢ In Indian scenario, poor communication & paucity of information was observed on SDM
  o Decisional conflicts were reported in majority of the patients in oncology clinical trials
  o Such lack of data may contribute to patient-reported harms, life disruptions and unnecessary financial costs

➢ India is majorly self-pay (out of pocket) market and currently involvement of the patient/family in SDM is limited
  o Involvement of patients is largely limited to tertiary care centres or else when the cost of therapy is high
  o In addition, cultural beliefs and prejudices impact the extent of participation
Communication failures were found to strongly correlate with the medico-legal malpractice litigations

- Studies have highlighted that ignoring or failing to diagnose patient preferences, puts clinicians at a higher risk of litigation

While policies are evolving to reflect a progressive shift in medical practice towards patient-centered care, the approach of shared decision-making has yet to become incorporated as usual care

The task is not easy, but the rewards for both patient and clinician can be considerable

To bridge the gaps from western world, the following efforts would be required:

- address different barriers at different levels of change; the individual users (professional and patient),
- linking of clinical practice guidelines with patient decision support
- reform of health professionals’ curriculum
- development of interactive decision making aids that helps the patient clarify their own preferences, weigh up the potential benefits as well as harms of alternative courses of action
- formation of guiding polices on SDM, its implementation to all health care facilities & periodic assessment on its implementation as well as utility
Discussion

➢ Many patients in India prefer the doctor to make decisions on their behalf, may be due to inadequate knowledge, seriousness of the disease, cultural beliefs and prejudices.
➢ Every patient is unique in their own views, values, preferences, and life circumstances, when it comes to choosing an appropriate treatment.
➢ The approach of involving patients in decision making has been debated due to conflicting findings about decision roles preferred by patients. In western world research, majority of patients wished to participate in decisions, however a subset of patients wanted to delegate decisions considering the severity of the situation.
➢ Failure to provide sufficient information about illness and treatment is the most frequent source of patient dissatisfaction. This is the underlying cause of the vast majority of formal complaints and legal actions.
➢ Recommended model by ethicists is: (1) ensure a shared understanding of the patient's illness; (2) present treatment options; (3) discuss the patient's values and lifestyle factors; (4) present a clear statement of recommended treatment options and invite patient choice.
➢ Health care providers have to be urged to integrate patients more actively as partners in decision making for cancer care. A collective efforts of Policy makers, Care givers and Patients required to bridge the gaps from the western world. Chances are high that millions of Indian are already eager to have the conversation
Conclusions

➢ Patients have a legitimate interest in learning about best practice, including evidence-based standards and treatment options. It is important to inform the patient and invite the patient and/or family for the preferred choice of one over the other.

➢ There is a large unmet need for SDM in current clinical scenarios in India, and gap from the western world is high.

➢ Assumptions that doctor (or nurse) knows best, making decisions on behalf of patients without involving them and feeling threatened when patients have access to alternative sources of medical information—this should have no place in modern health care.

➢ For doctors, the task is to determine which patients want to be offered choice and who will be ready for a more passive role. Decision making tools, developed on evidence-based research, can serve as a valuable instrument in facilitating SDM. Further research on patient-centered cancer treatment outcomes and the value of cancer treatment plans is required.

➢ If we broaden the concept of decision making beyond treatment decisions, we are sure many more opportunities exist for health care professionals to invite patients’ preferences across the care process.

➢ Will it work in India? Several hurdles need to be overcome.