

Involving the Family in Patient Care: A Culturally Tailored Communication Model

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Abstract

Background: Family involvement is a critical component of patient-centered care that impacts the quality of care and patient outcome. Our aim was to develop a patient- and family-based communication model suitable for societies with extended families. **Methods:** A multidisciplinary team was formed to conduct a situational analysis and review the patterns of family involvement in our patient population. Patient complaints were reviewed also to identify gaps in communication with families. The team proposed a model to facilitate the involvement of the family in the patient's care through the improvement of communication. **Results:** A communication model was developed keeping the patient in the center of communication but involving the family through identifying the most responsible family member. To assure structured measurable contact, mandatory points of communication were defined. The model streamlines communication with the family but maintaining the patients' rights and autonomy. **Conclusion:** Our proposed model of communication takes into account the importance of communication with the family in a structured way. The team believes that it is going to be accepted by patients who will be explored in the pilot implementation stage as the next future step.

Keywords: Communication model, family-oriented care, involving the family in patient care

INTRODUCTION

Why do we need family involvement in patient care?

Patient-centered care is one of the six domains of quality identified in the Institute of Medicine Report "Crossing the Quality Chasm."^[1] Involving the family in patient's care is critical as it has multiple benefits for the patients themselves, staff, and the organization [Table 1].

Family members (FMs) play important roles in the care of patients including contribution to decision-making, assisting the health-care team in providing care, improving patient safety and quality of care, assisting in home care, and addressing expectations of patient's family and society at large.^[2,3]

Societies vary in the structure and hierarchy of the family unit, and therefore, the size of extended families and the roles of different members among cultures. There are many factors affecting family dynamics including religion, educational, cultural, and legal variables, in addition to the prevailing health-care culture in relation to the family's involvement

in a patient's care. Middle Eastern and other developing countries share many issues related to family dynamics including large extended families that are heavily involved in patient care and committed to the personal care of their loved ones.^[4-6]

From our experience, extended families with diverse members background and educational levels represent a challenge to the health-care providers in terms of communication and family involvement and may lead to conflicts and dissatisfaction of staff and family.^[7-9]

Despite the call by different international bodies to increase patient involvement, there is no agreement to what is this involvement means and how it should take place.^[3,10-12]

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In this manuscript, we propose a communication model to overcome these challenges in societies with extended family.

METHODS

A multidisciplinary team was formed to address the family involvement in patient care at our hospital and propose an approach to involve the family systematically in the care plan. The team included members from the Intensive Care Unit (ICU), medical and surgical specialties, social services, religious affairs, patient services, and patient’s relation.

A situational analysis using strength, weakness, opportunities, and threats tool was done. Furthermore, the team reviewed various family and patient’s complaints and staff concerns. A review of the communication process revealed the need for streamlining the flow of information and improve the communication in standard fashion.

Current communication scheme

The team developed the current communication practice model which represents the real-life situations highlights the anarchy of communications with patients and families [Figure 1]. Health-care providers (HCPs) may have to talk to multiple FMs repeatedly delivering same information. This current practice may lead to frustration and wasted time and may result in conflict between the HCP and demanding FMs or among FMs themselves. The HCP may talk to FMs without the patient’s knowledge or approval, and sometimes different HCP teams may talk to different FMs resulting in confusion and conflicts.

This situation highlights the need for a new communication model that streamlines the flow of information between the HCP and patients and their families.

Table 1: Reasons to involve family in patient care

Providing relevant additional or different information
Contributing to decision-making
Assisting in providing care in the hospital
Improving quality and safety of care ^[17-22]
Providing care at home or outside the hospital
Patient, family, and societal expectation

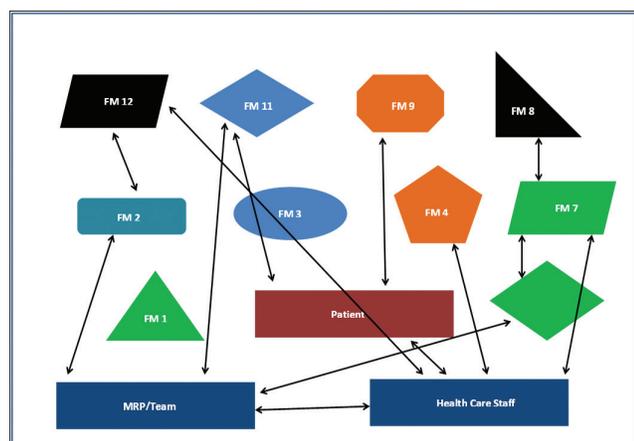


Figure 1: Current communication model. FM = Family member

The spectrum of family involvement

We serve patients of all ages with primary care to tertiary advanced care. Patients may have large number of siblings or children and first- and second-degree relatives involved in their care. Family involvement in decision-making spans over a wide spectrum. Table 2 provides the type of family involvement, the reasons and dynamics, in addition to giving real-life examples to illustrate the issue. From the team daily observation of family dynamics, it was clear that the involvement ranges from total voluntary withdrawal of the family to fully taking charge of decision-making without the approval of the patient.

RESULTS

The evaluation of the situation revealed the strong need to propose a standardized communication model to help in improving the interactions between HCPs, the patient, and FMs.

Components of the proposed communication model

The two major components of the communication model are identifying the most responsible FM (MRFM) and establishing points of communication [Figure 2].

Identifying the most responsible family member

According to our model, the unit of care includes the health-care teams, the patient, and the family. To streamline communication with the family, a single individual FM should be identified who will be the MRFM with the following characteristics:

- The MRFM may be different from the next of kin and should be appointed by the patient and be willing to provide continuity of care.
- The MRFM should be clearly identified to all members of the professional health-care team as well as the FMs.
- Accurate and up-to-date contact information for the MRFM must be readily available.
- The MRFM should be the first line of contact with the family, if communication is required. His/her responsibilities will be to communicate with other FMs.
- This does not replace the utilization of family conferences with other FMs, as needed.
- If a patient is not able to identify MRFM due to mental status changes or any other reason, next of kin according to local laws will be designated by HCPs to serve as MRFM.

The proposed communication model brings the family into the care unit in a structured way keeping the patients in the center of communication and introduces the MRFM as the second person in that patient-family team to have a direct line of communication. The sitter may be different than MRFM or the same person and may not be a FM at all. The model does not eliminate the communication with the rest of the family but it limits that to certain situations such as a request for a family conference.

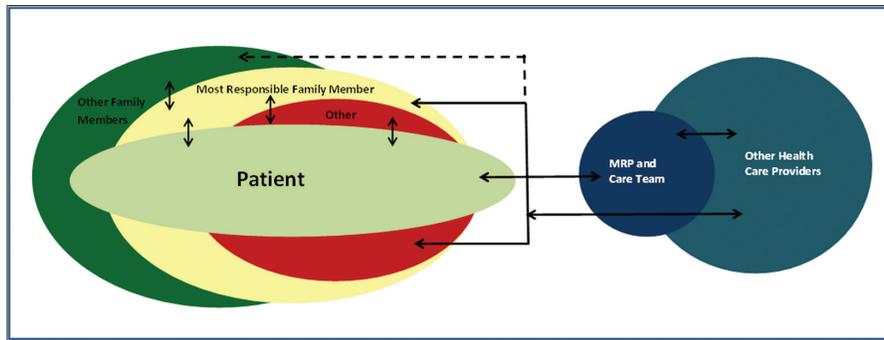


Figure 2: Proposed communication model between the patient, their family members, and staff. Solid lines represent direct communication is required, dashed line depicts communication is done on as needed basis. MRP = Most responsible physician

Table 2: Spectrum of family involvement in decision-making

	Not involved at all		Participatory	Fully making the decision		
Reason for involvement	Patient or family choice	HCP choice	Patient and HCP choice	With patient’s approval	Without patient’s approval	
Dynamics of involvement	Patient refuses, FM refuses, or FM does not show up	Oversight by HCP or by choice of HCP	Both patient and HCP invite and accept FM participation	Patient delegates decision-making to a particular FM	Making decisions without the patient’s knowledge	Making decision against the patient’s wishes
Real-life examples	A son dropped off his sick mother, left, and could not be reached A patient asked the family to leave the room to discuss his condition	HCP visits the patient, examines and talk to him, but they do not acknowledge other individual in the room HCP asked a FM to wait outside the room so that he can talk to the patient privately	Issues discussed openly with patients and FMs who provide advice and opinions to the patient and HCP, but do not impose the decision or take over the patient’s role	One of the patients asked HCP to examine her, allow her to leave the room, and then discuss the case with her brother	FMs try to make decisions on behalf of the patient without his knowledge of the choices or even his disease, citing fear of his mental well-being and general health	FMs may try to make a decision against the will of the patient

From left to right: increasing roles of FMs in decision making. HCP: healthcare provider; FM, family member.

Determining mandatory points of communication with family

To align expectations of all involved and be able to measure interaction, mandatory communication points are required. Our model proposes the following points:

- At the time of admission at the hospital
- During the discharge planning process and at the time of discharge
- Before any procedure (consent) and update after the procedure
- Any significant change in the patient or FM with the patient’s condition, especially life-threatening conditions
- Decision related to “No Code” or withdrawal of support
- On request of the patient or FM with the patient’s approval

The following is a case study illustrating the utilization of our proposed model in complex family scenario.

Deciding with families: A case study

A 56-year-old woman was diagnosed with advanced cancer and received all available chemotherapy over many years. There

was no other effective cancer therapy available at the time. She was admitted to the hospital for progressive dyspnea and chest pain. The reason for admission was symptom management and transition to a palliative care service for end-of-life care.

Family conflict about decision-making

Her husband refused referral to palliative care and demanded that the oncology service remains the primary service. Two brothers of the patient disagreed with the husband’s decisions and wanted to direct the care plan and they were supported by the patient’s two adult children. They did not want the husband to make decisions on the patient’s behalf. These differing opinions resulted in a full-fledged family conflict.

Few questions arose from this conflict including:

- Who should be involved in the decision-making?
- Who has the final say in these decisions?
- What about the involvement of other FMs?

Decisions had to be made regarding discontinuing further cancer therapies, making the patient “No Code” (do not

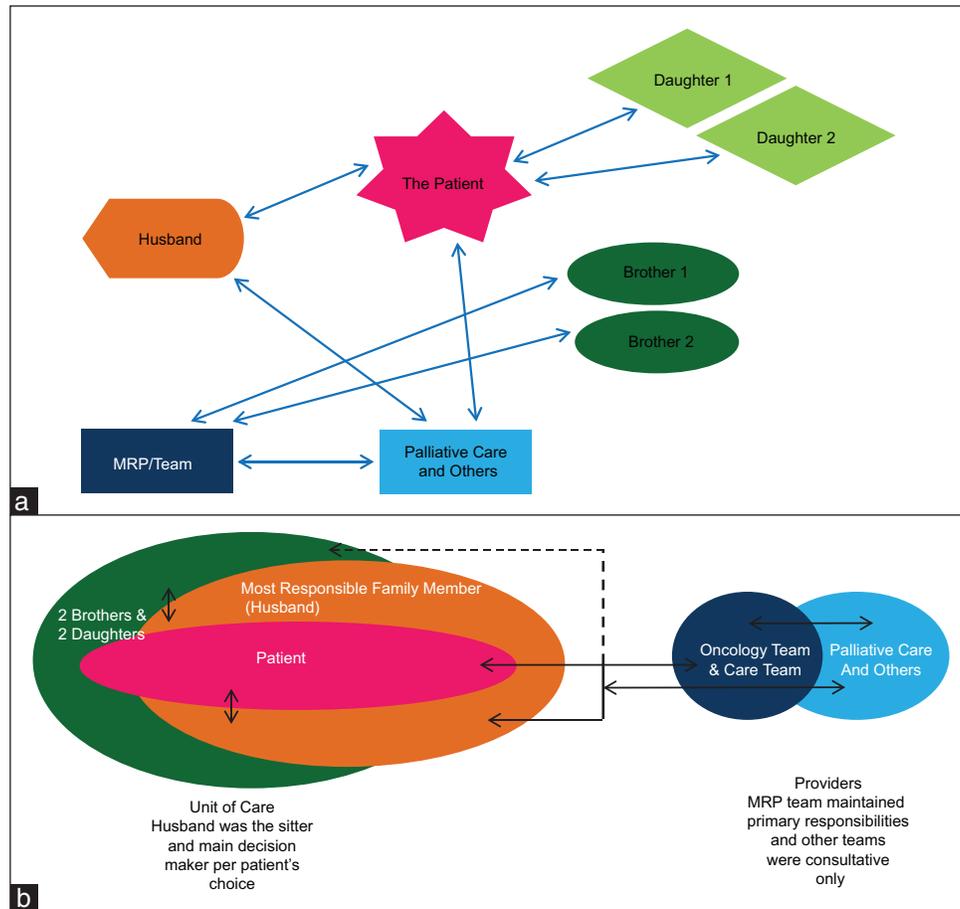


Figure 3: (a) Case study: Schematic illustration of patient care unit. (b) The anatomy of the family-oriented care communication model. MRP: most responsible physician. Solid lines represent direct communication is required, dashed line depicts communication is done on as needed basis

resuscitate) and arranging a transfer to palliative care. Figure 3a depicts the current family communication process.

Applying the communication model

We asked the patient about who should be the final decision-maker in terms of her health-care issues. Her answer was: “My Husband should make all decisions about my health.” The second question was if other FM should be informed about her condition? Her answer was: “Yes, but not to make decisions.”

From the discussion with the patient, we drew a new communication model [Figure 3b] making the husband the main decision-maker (on behalf of the patient per her request). He was also the sitter. The two brothers and daughters remained in the family unit to be informed but not to make decisions. The oncology team remained the primary care team and was consulted in terms of the palliative care as per the husband's request.

The patient expired peacefully with husband and other FMs at the bedside.

DISCUSSION

Communication with multiple members of the patient's family presented a challenge to our health-care delivery resulting

in repeated friction between staff and FMs and among FMs themselves. In addition, family involvement may encroach in many occasions on the patient's own rights and autonomy. Therefore, our model was developed based on our knowledge of the culture and family dynamics.

Although the model was developed based on experience in one setting, the model is applicable to any society as the guiding principles about family involvement, and patient's right and autonomy are the main consideration in this model. The model can be adapted to an individual patient which is very essential step in personalizing care.

As we advanced our knowledge in precision medicine and we know how to select the best treatment for the patient, communication with patient and family should be also personalized. This model will enable a health-care professional to do so. Developing a communication model will help in many ways including improving patient care the satisfaction of patients, their family, and the staff. Assuring proper and structured family involvement which will help to improve the patient's care as FMs can provide information that the patient may not know, notice, or remember. They will help take care of the patients in the hospital and at home. The improvement of quality of care and patient's safety is also expected outcome

in family-centered care model. Supporting patients in his care and decision-making will help reduce the pressure from the patients.

Damaging conflicts could happen as a result of miscommunication, especially if there was an abrupt change in the patient's condition.^[13,14]

While others developed communication models, these models were specific for certain setting, not generalized and tackle one aspect of communication.

For example, Workman proposed communication model for end-of-life care.^[15] This model focuses only on end-of-life care and the points of communication which related only to the treatment decision. The model does not describe how the family should be involved like we did in our model.

Other investigators reported structured family involvement in certain settings such as cardiopulmonary resuscitation or ICU rounds, but these are special situations that do not cover the whole spectrum of the patient journey with the disease.^[16]

With the application of this model, it is anticipated that HCP will have less conflicts, will save time and energy resulting from talking to many FMs and confusion about whom to talk from the family. Our model is adaptable to any individual patient or setting and it maintains the focus on the patient and brings the family in a proactive structured way.

CONCLUSION

In summary, involving the family in patient care is more challenging in societies with large families. Applying the proposed communication model should facilitate this involvement and enable the family to participate in the patient's care without negating the patient's autonomy and rights. We plan to pilot test the model in our hospital in escalating fashion to determine the best approach to utilize this model and adjust accordingly.

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Conflicts of interest

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