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“The problem often is that we do not have a family spokesperson but a spokesgroup”: Family Member Informal Roles in End-of-Life Decision-Making in Adult ICUs

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Abstract

Background—To support the process of effective family decision-making, it is important to recognize and understand informal roles various family members may play in the end-of-life decision-making process.

Objective—The purpose of this study was to describe some informal roles consistently enacted by family members involved in the process of end-of-life decision-making in intensive care units (ICUs).

Methods—Ethnographic study. Data were collected via participant observation with field notes and semi-structured interviews on four ICUs in an academic health center in the mid-Atlantic United States from 2001 to 2004. The units studied were a medical ICU, a surgical ICU, a burn and trauma ICU, and a cardiovascular ICU.

Participants—Participants included health care clinicians, patients, and family members.

Results—Informal roles for family members consistently observed were: Primary Caregiver, Primary Decision Maker, Family Spokesperson, Out-of-Towner, Patient Wishes Expert, Protector, Vulnerable Member, and Health Care Expert. The identified informal roles were part of family decision making processes, and each role was part of a potentially complicated family dynamic for end-of-life decision-making within the family system, and between the family and health care domains.

Conclusions—These informal roles reflect the diverse responses to demands for family decision making in what is usually a novel and stressful situation. Identification and description of these family member informal roles can assist clinicians to recognize and understand the functions of these roles in family decision making at the end-of-life, and guide development of strategies to support and facilitate increased effectiveness of family discussions and decision-making processes.

Keywords

informal family roles; family roles; end-of-life decision making; intensive care units; critical care; adults

Introduction

Health care clinicians in a setting such as an intensive care unit (ICU) are part of an institutional social system and are linked through a variety of relationships. They fill formal roles (e.g., nurse, physician), exercise rights and privileges, and are expected to discharge obligations and responsibilities in conformity with established values, norms, and rules for behavior.¹ Similarly, persons in a family comprise a small social system; they function in a different socio-cultural domain. They occupy formal roles (e.g., mother, son), exercise rights and privileges, and discharge obligations and responsibilities in conformity with established family values, norms, and rules for behavior. When one member of a family becomes a patient in the ICU, members of these two domains come into dynamic interaction with each other. Family members are often involved in decision making for withdrawal of life-sustaining treatment.²

Sometimes one family member has been named the legally designated surrogate end-of-life decision maker for ICU patients who have lost capacity (Health Care Proxy or Agent); this formal role has been studied extensively.³⁻⁸ Although, one family member is asked or expected to be the “voice” for the patient by clinicians involved with the patient’s care, the family in this setting often includes several family members who become involved in the process of end-of-life decision making. Under these circumstances, the complexity of the end-of-life decision-making process can escalate. This has been found to not only affect the level of tension associated with end-of-life decision-making, but also the satisfaction of family members involved.^{9, 10} To understand and support the process of effective family decision-making, it is important to understand informal roles various family members may play in the end-of-life decision-making process.

The findings reported in this article are part of a larger study of the socio-cultural contexts for end-of-life decision-making in ICUs.¹¹ In a previous article¹¹ we focused on variation in cultures of different ICUs related to end-of-life decision-making; the focus of this article is on the various informal family roles that emerged from the data that are expected of and engaged in by family members during end-of-life decision-making in an ICU.

Formal family roles are not culturally defined to address every circumstance, nor to accommodate the personal characteristics of families and their individual members. Families functioning in an ICU context are not in a usual setting for family life. Informal roles emerge in the context of situational demands and describe how people actually behave in particular situations, rather than how they are expected to behave.¹² Informal roles can reflect responses to the common situational demands of any small system, including families, and a number of these roles have been previously identified. They include the *scapegoat*, who may be seen as the problem when negative emotions threaten the system, and the *deviant*, whose behavior helps clarify system boundaries by challenging norms.¹³ The emergence of informal roles of clinicians specific to the developing small system of the health care team also has been studied.¹⁴

Study of informal role behavior is particularly useful in the situation of family members in the ICU as family members have no agreed upon normative “script” for their behavior. Informal roles emerge in this context to help fill the gaps in how family members respond to the novel challenge of end-of-life decision-making.¹⁵⁻¹⁸ Recognizing and understanding the informal roles that family members may play in this setting can help guide clinicians in their strategies for working with family members in end-of-life decision-making.

Design and Methods

This was a prospective ethnographic study. Data were collected on four ICUs in an academic health center in the mid-Atlantic United States from 2001 to 2004. The units studied were a medical ICU (MICU), a surgical ICU (SICU), a burn and trauma ICU (BTICU), and a cardiovascular ICU (CVICU).

The university institutional review board for human subjects protection approved the study. All interviewed participants signed informed consent forms. A full description of the study design has been reported previously.¹¹

Participants

Participants included health care clinicians, patients, and family members interviewed in relation to specific cases or in general on end-of-life decision-making. When possible we interviewed clinicians and patients or family members involved in the same situation. If decision making continued over several days, participants were approached for another interview to assess changes and explore questions raised by field observations and earlier interviews. The total number of interviews conducted was 157, with 130 participants. The interviews were with the following categories of participants: 46 interviews with 30 physicians, 60 interviews with 48 nurses, 13 interviews with other providers such as clergy, social work, ethicist, and pharmacist, 4 patient interviews and 34 interviews with 38 family members. Fieldnotes were included in the analysis, along with recordings from 22 family meetings.¹¹

Methods

A 6-member research team used participant observation, field notes, and semi-structured interviews to examine the end-of-life decision-making process from different participants' perspectives. The semi-structured interviews were audio-taped and lasted from 15 to 60 minutes. For this analysis, we focused on interview questions specific to the participation of family members, including questions related to their relationships with the patient, with other family members, and with health care clinicians; their involvement in the decision making; and problems or disagreements related to the decision making process. Medical record information was used to identify some circumstances of decision making, for example, the patient's condition and availability of advance directives.

Procedure

Data were collected for approximately 5 hours a day, 5–7 days a week for 7 months on each unit sequentially (>700 hours per unit). Once a potential end-of-life decision-making situation was identified, the attending physician was asked for permission for a research team member to contact the patient and/or family. Data collection began as soon as possible. Patients were followed by the research team until the patient's death or discharge from the ICU.

Data Analysis

All the tapes were transcribed verbatim and reviewed for accuracy. Transcribed corrected interviews, family meetings, fieldnotes, and chart data were dated and entered into the ATLAS.ti program.¹⁹ Analysis, using an ethnographic approach,^{20, 21} began at the time of the first observation and continued throughout the study.

Small group and family dynamics theories informed the understanding of family informal roles in end-of-life decision-making in ICUs that were identified in data analysis. In the analysis for this article, we used data coded as "Roles-Family," which was defined as

various key roles that family members played in end-of-life decision-making. This general code was generated in our early analysis and subsequently was divided into sub-codes for the specific informal roles of family members in end-of-life decision-making that consistently emerged as data analysis progressed.

Results

Eight informal roles that family members engaged in during the end-of-life decision-making process in these ICU settings were identified. They were: Primary Care Giver, Primary Decision Maker, Family Spokesperson, Out-of-Towner, Patient Wishes Expert, Protector, Vulnerable Member, and Health Care Expert.

1. The Primary Care Giver

If family care-giving was involved prior to ICU admission, the Primary Care Giver was a role of the family member who had spent the most amount of time caring for the patient prior to hospitalization. One spouse said:

After she had the stroke I took care of her naturally. I'm her husband. I did everything for her or whatever. I made sure that she's had therapy... I mean I've looked out for her best care the best I could. I don't know -

When a loved one was admitted to the ICU, the Primary Care Giver was confronted with the reality that it was no longer possible for him/her to care for the ill family member. This previously important role was de-activated in the hospital setting. The same spouse explained:

.....I'm using his [doctor's] judgment [now]. That's why I brought her. I can't take care of her. I can't – I've gotta use their judgment...

The Primary Care Giver often experienced great emotional angst over relinquishing this role to hospital personnel. Often clinicians expected a quick shift of the Primary Care Giver into the role of Primary Decision Maker for treatment decisions in the ICU. A family member of another patient stated:

He [doctor] did say go with the way you feel but he also said if that was my wife or my daughter, I would remove life support, and I said but I can't do that. Something in my heart is saying we've got to give her more time.

2. The Primary Decision Maker

As others have described,^{3, 7, 22} the Primary Decision Maker role emerges in families as a response to the demands for surrogate end-of-life decision making. Sometimes a family member fulfilling this role was formally designated (e.g., in the patient's advance directive). Whether this had occurred or not, ICU clinicians sought one individual to become the Primary Decision Maker, a family role viewed by clinicians as central to the end-of-life decision-making task when the patient was incapacitated. As one social worker described this role:

....probably the people I work with the most in these situations are the decision makers, you know, the primary people in the family that are there the most and taking the lead and initiative to make the decisions that provide the care.

Often families had multiple decision makers rather than one Primary Decision Maker as preferred by the clinicians.

The Primary Decision Maker frequently conversed with other family members in the decision making process, and the burden of decision making could be shared informally

amongst family members. Family language around decision making often contained “we” as the referent, reflecting this shared decision making process. A striking example from the fieldnote data illustrates this process of sharing in the decision making and in the decision itself. The family acted in concert to support the Primary Decision Maker.

[The physician] gets the DNR order sheet out and goes over the entire form with the family. He then asks which one is the proxy. [A daughter] says she is; he asks her to sign. [Another daughter] says, “We all want to sign, we don’t want only [named proxy] to feel like she’s the one who did this.” [Two sons] immediately agree; and [one daughter] hugs [the other daughter] who is teary. [The physician] says there is room for everyone to sign. They all sign the form.

If multiple decision makers were not acceptable to clinicians or family members, either a clear single Primary Decision Maker emerged or the Primary Decision Maker role was contested.

On the other hand, discussion could become too inclusive as shown in the following example from a family meeting, where family friends exerted their own opinion in the decision making process.

[Friend of family]: Maybe he [patient] won’t do it [recover] as quickly as a 20 year-old. But they want their father, and she wants her husband. And that’s what we should be focusing on, rehabilitation, getting him up and getting him going.

Physician: Well, I think it’s always important and the thing I was asking [his wife] about. I think there’s nobody in the whole world better able to speak to the desire of her husband than she. And I think sometimes families forget that what they really want is what’s best for their loved one.

3. Family Spokesperson

One informal family role, Family Spokesperson, was encouraged by clinicians because of the clinician’s wish to address families’ needs for information efficiently and to facilitate the decision-making processes. Despite the complexity of many families’ internal decision making processes, many clinicians preferred a single Family Spokesperson as reflected in the staff quotation included in the title of this article --“The problem often is that we do not have a family spokesperson but a spokesgroup.” The nurse manager of one ICU spoke of the formal process expected on their unit to be followed to identify the Family Spokesperson.

What we ask is.... there be a family Spokesperson that we can give information to, and we ask that that family spokesperson disseminate the information to the other family members.... if somebody calls in, it needs to be the Spokesperson....

At least three ICUs had this role formally identified in the visitor brochure they provided, which included visitation policy and asked for an individual name with contact information to be placed in the medical record and care plan. Some units were inconsistent with identifying and documenting an individual family member for this role. Further, although this was constructed on several units as a formal role for one family member, we found that some families would informally evolve this role to include other members. While the tendency was for the hospital staff to confound the roles of Spokesperson and Primary Decision Maker, it was observed that a family member who acted as a Spokesperson with hospital staff was not necessarily the Primary Decision Maker (e.g., an adult child as spokesperson for a parent who was making final decisions).

Families, especially when there was disagreement among members, often were reluctant to identify one member as the sole Spokesperson. Regardless of whether there was a formal unit process of identifying the Spokesperson or not, efforts were made to seek one out by

clinicians and staff when a problem arose. However, at times, we observed that any family member who was convenient, at the bedside or in a visitor waiting area, was approached by a clinician and offered information or asked questions about the patient. This clinician behavior conveyed a message that any family member present could be a Spokesperson, but this was also seen as contrary to the formal rule regarding identification of one Family Spokesperson. One RN expressed this situation well:

“...some nurses will talk to all--a lot of different family members about what's going on. That makes it very, very difficult. I think... that it's very important to have it be [the] Family Spokesperson. Just one person should be the proxy [sic] to whom that information is going to.”

4. The Out-of-Towner

Complex family dynamics of decision making were apparent through other family informal roles identified. One such role was the Out-of-Towner, a family member who had not been involved in the daily care giving and may not have been engaged during the early ICU stay and, therefore, often brought a different perspective to the in-town family's end-of-life decision-making discussions. End-of-life decisions often were put on hold until other family members could communicate with out of town relatives and they could be part of the discussion about the patient's condition and the status of decision making thus far. Because they were from out-of-town, they often also had time limits on their ability to be physically present in the situation and, if present, might be eager to have a firm decision made before their departure. Consequently, their involvement added complexity to the decision-making process and could create conflict within the family and with clinicians. An example of this is a brother who described his perspective on his out-of-town sister's role in decision making about their father:

“My sister was--you have to take a lot of things into consideration. She is the child from out of town. She is the one that feels that she has to have this whole thing fixed before she can go home. She is the one that doesn't have the time to wait it out. This illness is a wait out.... She is trying to get this whole thing fixed before she goes home. She has to go home and I understand that. She just has to leave and trust that it's gonna happen correctly....”

Clinicians perceived the Out-of-Towner as a family member whose views could complicate the decision-making process, as shown in this quotation from a physician:

....especially where family members may not all be in the same city. So, they have not seen mom or dad, [and] you will be in a family meeting and, the one [local] daughter will say, “Look, I'm with Mom all the time; I know what she wants. You see her twice a year. How do you know what she wants?”

This example illustrates another emergent family informal role related to decision making, when the family had not achieved consensus about what the dying family member's wishes might have been as a guide to that decision making.

5. The Patient's Wishes Expert

Being Primary Decision Maker was difficult, but family members were much more likely to come together in support of a Primary Decision Maker and collectively to feel confident they were following the patient's wishes in the context of known patient preferences. In the context of unknown preferences, decision-making was often much more difficult for the Primary Decision Maker and preferences were much more open to differing interpretations by other family members of what the patient ‘would have wanted’. The Patient's Wishes

Experts were family members who claimed their interpretation of the patient's wishes was the correct interpretation.

[son] You have to listen to everything my father says.....it's like his living will. I read it, and I know what my mother and sister said, and I said wait a minute, my father doesn't want to be intubated, I understand that. Okay, if he is brain dead, he doesn't want to be intubated; but he is alive, he can get better. My father wants to Live; he is afraid to die. This is something that has been on his mind for 10 years.

When this role was enacted by several family members with different interpretations of the patient's wishes, end-of-life decision-making was often prolonged and inconclusive.

6. The Protector and 7. The Vulnerable Family Member

In this a situation a family member who might typically be expected to be the Primary Decision Maker was viewed as vulnerable for some reason, and another family member asserted family decision making authority to protect the Vulnerable Family Member. Commonly, these paired roles emerged when adult children believed they needed to protect an older parent (e.g., spouse of the ill family member) from the stress of end-of-life decision-making. An example was a daughter who was concerned about her mother being expected to decide about withdrawal of the ventilator from her husband, resulting in end of life too quickly for the mother to handle emotionally. The daughter stated: "Taking him off the respirator is only going to change things by hours, and I think that that would be way too painful for my mom given the rapidity of this event." If the vulnerable member did not accept that role, it caused family conflict that made the decision making process more difficult and delayed the decision making process.

Occasionally, patients had at least some capacity for decision making. However, in such circumstances they could be identified by family members as the vulnerable member. The quotation below is about a woman dying who was intubated but aware. Her husband had been very involved in the decision making and wanted her included in any decision about reintubation if extubation failed. However, some negative information about her condition, known to her husband, had been withheld from her at the husband's request. He questioned whether she would be able to make a decision about reintubation, especially when she did not have all of the relevant clinical information.

[husband] I'm trying to—I'm trying to think if her choice would be a real choice, to her. Because I would be okay with whatever her choice was so I'm trying to think, would it be a real choice? Would she know that that's a real choice and her deciding, and it might be....because she doesn't like that and maybe she had enough of it and she doesn't want it. Or maybe she'd say, "Yup, if I start to lose it, put it back in."

Even though in this rare ICU situation the patient had capacity to participate, her Protector family member saw her as vulnerable, remained in charge of the family end-of-life decision-making process, and asked clinicians to withhold some information about her condition from her.

Another fieldnote observation illustrates the Patient's Wishes Expert *and* the paired set of family informal roles of Protector and Vulnerable Member roles occurring in the context of a clinician looking for consent to perform a procedure. He asked:

...they [mother and father, father is the patient] have been married for 52 years. He [father] never let her [mother] make a decision in 52 years. You are gonna let her [mother] cut her teeth on this one? No, she is not cutting her teeth on life or death. I'll do that. I will give mom my feelings on that and I'm not gonna subject her

[mother] to making that decision. I think I know what he [father] wants, so that's what I told her [mother]."

In this example, the son claims his own expertise in knowing his father's preferences (or wishes). He also was prepared to protect his mother from having to make a life and death decision about her husband. He saw his mother as vulnerable because, in his view, she had never made decisions during 52 years of marriage.

8. The Health Care Expert

The Health Care Expert was a family member who could influence decision making in the family system through a claim of clinical expertise by virtue of some connection to the health care domain (e.g., nurses, physicians). Family members and sometimes clinicians viewed this role as one that had the potential to facilitate the decision making process. The Health Care Expert might utilize resources to bridge the gap between the two domains, whereas family members who lacked this expertise struggled more with the situation and with end-of-life decision-making. Family members often relied heavily on the family Health Care Expert for direction in the end-of-life decision-making process. The quotation that follows illustrates the role of the Health Care Expert, in this case a daughter who was a licensed practical nurse:

[daughter, LPN] My brothers and sisters never thought of the antibiotics and you know, I think sometimes you have a little more knowledge. Whether you understand things better, which is why they [my family members] put me down as the Spokesperson. Which is why she put me down as her [proxy]....

Clinicians' reactions to family Health Care Experts could be mixed: on the one hand, sometimes they were viewed as able to understand medical situations and expected to be "reasonable" about the treatment decisions or more in line with the clinicians' way of thinking. An example of this is expressed by an RN:

I think her mother deferred to her [daughter] the physician.... It is definitely nice when the family is so knowledgeable about what is going on that, you know, they realize as you realize, at almost the same time, that this is...that CPR would be futile....

Other Family Health Care Experts challenged the thinking and recommendations of the ICU clinicians, as well as the quality of care that their family members were receiving, stimulating conflict between the family and clinicians. A good example of this from fieldnotes is when a group of RNs talked one day about a patient's son-in-law, who was a physician. On the phone he had yelled at one of the RNs and then had hung up. From the RN's perspective, he had conveyed that the nurses were all incompetent. When family Health Care Experts did not agree with the clinicians, there was an element of surprise and frustration expressed, as this resident physician viewed it: "Granted that her son-in-law is a physician but we are still not getting through."

The situation got even more complicated when more than one family member could claim a role as Health Care Expert, and the different "experts" were not in agreement. Family members could also "call in" friends who were health care clinicians to play the role of Health Care Expert for the family or some sub-group of the family; again, the "call in" of multiple experts could complicate the decision making process.

Discussion

As illustrated in these results, the identified informal roles were intricately tied to the family decision making process, and each helped to create a potentially complicated family

dynamic for end-of-life decision-making, within the family system, and between the family and health care domains. In their expectations for end-of-life decision-making, clinicians, on the other hand, often pushed for a single family member to be both Primary Decision Maker and Family Spokesperson to facilitate communication and decision-making. However, our findings suggest that this often did not happen and made the process more complicated than desired by clinicians.

These eight informal roles did not all emerge in every family. More than one role might be assumed by a single family member (e.g., the Out-of-Towner could also be the Health Care Expert) or the informal roles might be shared among multiple family members. Whether these informal roles facilitated decision making or escalated family conflict or family/clinician conflict depended on the family context (i.e., family history and culture around difficult decision making). In situations where other family members interacted to support a single member both as Primary Decision Maker and Family Spokesperson, consensus within families was more easily achieved.

In other families where there was less cohesion, as more family members became involved, there was a greater proliferation of informal roles in the decision making process, potentially more conflict and disagreement, and a more difficult time with making end-of-life decisions. When there was no consensus among family members around end-of-life decision-making, informal roles might be used to leverage a decision in a way that advanced the role of the person in the family system, for example by claiming to be a Protector or Health Care Expert.

Jockeying for position in the family system can be viewed as a consequence of the removal, by life-threatening illness, of a member of the system and a scramble for a new status in that altered system. Thus, for example, with the removal of an ill parent, adult children might move to claim status and authority in the system previously held by that parent.

In either circumstance of cohesive or conflict-prone family decision making processes, ICU clinicians who attempted direct communication through identification of a Family Spokesperson often found that there was a “spokesgroup” of family members playing differing informal roles but all wanting input into the decision making process either directly or indirectly. As others who have studied family involvement with end-of-life decision-making have found, the decision to withdraw or withhold treatment generally includes multiple family members,²³ and communication needs for families often go unmet.^{9, 24, 25}

Recognizing and understanding the roles family members play within the family unit during critical decision making is important in facilitating more effective interaction and consensus among family members and reducing conflict among family and clinicians. Interventions limiting conflict and strengthening family supports should be a major goal, but the manner in which this is done needs to incorporate the cultural differences of families and expertise of clinicians.

Family meetings with clinicians, when held, can make these complex roles involved in family end-of-life decision-making visible. Family meetings can also reduce conflict between clinicians and family members regarding frustration with not having one person as Family Spokesperson and/or Primary Decision Maker.²⁵ More recently there has been an increased emphasis on conducting effective family meetings within critical care as well as use of other services, such as palliative care services, that may be called to consult if the process of decision making becomes problematic.²⁶ Awareness of the potentially complicated dynamics associated with some of these family informal role processes may assist clinicians to seek earlier consultation.

Limitations

Although the purpose of qualitative research is not to make broad generalizations but to examine the depth of individual experience in a phenomenon such as end-of-life decision-making, there are limitations to this study. First the study was conducted in one setting, a university medical center, although different types of ICU units were included to capture cultural differences regarding end-of-life decision-making among the units (Baggs et al., 2007). The data were collected some time ago; however, the nature of the data and analyses reported here, as well as the results, concerning informal roles in family decision making processes in critical care situations, are not likely to “age” quickly, as family systems processes, such as decision making processes identified are fundamental to family life. The approach taken to analysis is theoretically informed, drawing on a rich body of theoretical literature related to informal roles in family systems, family crisis responses, and small group functioning, which became relevant as we explored the data.

The presence of the researchers and the process of audiotaping during family meetings and interviews could have influenced the responses. We only describe the results of participants who agreed to participate, although few potential participants who were approached refused to participate. Finally, we do not claim to have exhausted potentially identifiable informal family roles. There may be other informal roles that did not emerge in these data either because we missed them in our analyses, they are infrequent, or they do not play as prominent a role in the end-of-life decision making process.

Conclusions

End-of-life decision-making for patients in ICUs involves an intersection of both the health care domain and family domain. Promoting family responses to end-of-life questions that honor the wishes of the patient requires an understanding of informal family roles such as those observed and described, as well as an awareness of how these roles may be enacted. Strategies need to be developed to facilitate smooth resolution of conflicting views and decisions among family members and between clinicians and family members that foster effective decision making processes. Potentially fruitful areas for further exploration include the identification of other important informal family roles that may be less prominent or less frequently portrayed but may be equally important in some end-of-life decision-making, and the role of advance directives in family end-of-life decision-making processes. A closer examination of family meetings as a way to foster effective family end-of-life decision-making and the role of hospital-based palliative care services in supporting effective family end-of-life decision-making processes are vital areas for further study.²⁷

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Summary of Key Points

Recognizing and understanding the roles family members play within the family unit during critical decision making is important in facilitating more effective interaction and consensus among family members and reducing conflict among family and clinicians.

- To support the process of effective family decision-making, it is important to recognize and understand informal roles various family members may play in the end-of-life decision-making process.
- Eight informal roles that family members engaged in during the end-of-life decision-making process in ICU settings were: Primary Care Giver, Primary Decision Maker, Family Spokesperson, Out-of-Towner, Patient Wishes Expert, Protector, Vulnerable Member, and Health Care Expert.
- The identified informal roles were intricately tied to the family decision-making process, and each helped to create a potentially complicated family dynamic for end-of-life decision-making, within the family system, and between the family and health care domains. In their expectations for end-of-life decision-making, clinicians sought a single family member to be both Primary Decision Maker and Family Spokesperson to facilitate communication and decision-making. However, our findings suggest that this often did not happen and made the process more complicated than desired by clinicians, but more in line with how families function.
- Interventions limiting conflict and strengthening family supports should be a major goal, but the manner in which this is done needs to incorporate the cultural differences of families, the various roles family members play, and the expertise of clinicians.