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Family Matters: Effects of Birth Order, Culture, and Family Dynamics on Surrogate Decision Making

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Abstract

Cultural attitudes about medical decision making and filial expectations may lead some surrogates to experience stress and family conflict. Thirteen focus groups with racially and ethnically diverse English- and Spanish-speakers from county and Veterans hospitals, senior centers, and cancer support groups were conducted to describe participants' experiences making serious or end-of-life decisions for others. Filial expectations and family dynamics related to birth order and surrogate decision making were explored using qualitative, thematic content analysis and overarching themes from focus group transcripts were identified. The mean age of the 69 participants was 69 years ± 14 and 29% were African American, 26% were White, 26% were Asian/Pacific Islander, and 19% were Latino. Seventy percent of participants engaged in unprompted discussions about birth order and family dynamics. Six subthemes were identified within 3 overarching categories of communication, emotion, and conflict: Communication – (1) unspoken expectations and (2) discussion of death as taboo; Emotion – (3) emotional stress and (4) feelings of loneliness; and Conflict – (5) family conflict and (6) potential solutions to prevent conflict. These findings suggest that birth order and family dynamics can have profound effects on surrogate stress and coping. Clinicians should be aware of potential unspoken filial expectations for firstborns and help facilitate communication between the patient, surrogate, and extended family to reduce stress and conflict.

Keywords

Advance care planning; Birth order; Decision Making; Aging; Qualitative research

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INTRODUCTION

Making medical decisions in the context of serious illness is stressful, especially for surrogate decision makers. Although advance directive forms were developed in part to ease the burden of surrogate decision making, [1-3] a growing body of literature demonstrates that surrogates often feel unsupported and experience emotional burden and post-traumatic stress. [4-6] Understanding the factors associated with surrogate stress is critical given the important role of surrogates in end-of-life decision making. [7, 8]

Cultural attitudes about end-of-life and surrogate decision making differ, [9, 10] and many cultures do not adhere to Western views on autonomy - the cornerstone of traditional advanced care planning (ACP). [9, 11] For instance, racial/ethnic minorities traditionally have low advance directive completion rates and some groups, such as Asians and Latinos, traditionally rely on the family model of medical decision making.[12-14] Consequently, decision support and caregiving is often provided by close family during serious illness and at the end of life. [12-14]

There is a paucity of research about the role of birth order in surrogate decision making. Although all children have equal legal standing as default medical decision makers in most states,[15] family research has shown that firstborn children are often perceived by parents to possess strong responsibility traits, and are more likely to be designated the surrogate decision maker and caregiver than younger siblings.[16] This study, however, used hypothetical scenarios and included predominantly white participants. One qualitative study of South Asians in the U.S. demonstrated that children, especially firstborn sons, have a strong sense of family duty and that complex family dynamics can lead to decisional conflict.[12]

To provide adequate preparation and support to surrogate decision makers, it is important to understand the filial expectations and family dynamics of diverse cultures. Therefore, using data from a series of focus groups centered on end-of-life decision making, [17]we explored filial expectations and family dynamics related to birth order and surrogate decision making among a racially and ethnically diverse sample.

METHODS

Study Design and Sample

This qualitative study used focus groups to explore medical decision making in serious illness. A racially/ethnically diverse sample was recruited through convenience sampling and study fliers from primary care clinics at San Francisco General Hospital, the San Francisco VA Medical Center, cancer support groups, and senior centers. Individuals were eligible if they were 18 years of age or older and reported having made serious medical decisions for themselves or someone else. Serious medical decisions were defined as a decision that involved receiving life-prolonging treatments such as mechanical ventilation, major surgery, chemotherapy, or care in an intensive care unit. Individuals were excluded if they did not speak English or Spanish; if they reported being deaf, blind, or demented; or if

they were assessed to have moderate cognitive impairment (<19/50 on the Telephone Interview Cognitive Status (TICS) questionnaire).[18] The Institutional Review Boards at the University of California, San Francisco and the San Francisco VA Medical Center approved this study. All participants signed written informed consent forms.[19]

Focus Groups

To create the focus group guides, input was obtained from researchers in geriatrics, decision making, health literacy, and ACP. [20]The original study goal was to investigate what best prepared individuals to make medical decisions for serious illness. The focus group guide explored past experiences with decision making and experiences with discussions about death and dying.[17] Although the focus group guide included vignettes involving families, questions about family dynamics or issues related to birth order were not explicitly asked and information obtained about filial expectations was unprompted.

Thirteen focus groups were conducted, including 3 dedicated Latino groups, 2 African American, 2 Asian/Pacific Islander and 6 mixed race/ethnicity groups. The groups had a mean sample size of 5 ± 2. All groups were audio-recorded and transcribed verbatim. The English focus groups were moderated by two clinicians specializing in end-of-life decision making, and Spanish focus groups were moderated by a Spanish-speaking co-author (RM) and a native Spanish-speaker. Although individuals were included if they made decisions for themselves or for someone else, the majority (80%) spoke from both perspectives (i.e., they had played both the patient and surrogate roles during their life) and their responses were combined in the analysis.

Demographic information was collected on self-reported age, gender, and race/ethnicity. We did not collect information on birth order because decision making experiences were the main intent of the initial focus groups.[17]

Data Analysis

Focus group transcripts were analyzed using a standardized, iterative framework approach.[21] Through several independent readings of the transcripts,[20] authors RM and RS used an iterative process of thematic content analysis to develop a coding scheme, [22, 23] using NVIVO 8® software (QSR International, Burlington, MA). The coding scheme was consistently refined through the constant comparative method.[24] Overarching themes were identified and disagreements were resolved by consensus. Trustworthiness was ensured through clear inclusion/exclusion criteria, standard interview guides and coding schemes, and an audit trail for coding. Trustworthiness was evaluated through calculation of the concordance of applied codes to the same segments of text. Concordance reached 84% between authors RM and RS; a rate comparable to other studies.[25, 26]

Participant characteristics were described with percentages and means. To explore whether filial expectations about birth order and family dynamics were identified more frequently by racial/ethnic subgroups, the number and percentage of participants who discussed these themes by race/ethnicity were calculated. Given the qualitative nature of this paperand the lack of questions about family dynamics in the focus group guide, these analyses are considered exploratory only.

RESULTS

Participant Characteristics

The mean age of the 69 focus group participants was 69 ± 14 years and 74% were non-white. (Table 1)

Six subthemes related to filial expectations and the role of firstborn children in surrogate decision making and caregiving were identified within 3 overarching categories of communication, emotion, and conflict: Communication – (1) unspoken expectations and (2) discussion of death as taboo; Emotion – (3) emotional stress and (4) feelings of loneliness; and Conflict – (5) family conflict and (6) potential solutions to prevent conflict. Overall, 49 participants (71%), from all race/ethnic groups, discussed these issues unprompted, including 85% of Latinos, 80% of African Americans, 72% of Asian/Pacific Islanders, and 44% of Whites (Table 3). Fourteen of the 69 participants (20%) did not mention prior experiences making medical decisions for others and therefore, did not substantively contribute to the analysis.

COMMUNICATION

Unspoken Expectations

Many participants discussed unspoken expectations of their role as the eldest and that it is often assumed that the firstborn will be the primary decision maker for the family (see Table 2 for all quotes). For instance a Latina woman who had cared for her mother with lung cancer stated, *"Because I'm the oldest, out of 8 kids, she put me in charge."* Even younger siblings appeared to respect birth order and would defer to the oldest. For instance, a younger African American sibling who had cared for her mother stated, "*I stood back. I wasn't going to fight them (older siblings) on anything."*

Several individuals spoke about how the oldest child does not need to be formally asked to take on the decision making responsibility or have their role as surrogate discussed because it is implied. As a firstborn son pointed out, *"The philosophy of the Asian people – the eldest in the family makes the decision. It doesn't have to be written down. It doesn't have to be pointed out."*

Many firstborn children spoke about how this assumption about their role often led to a lack of discussion about their parents' wishes and preferences, leaving the surrogate feeling unprepared for medical decision making. An Asian woman who had made medical decisions for her parents said, *"'You're oldest. You make the decisions.' But you're (the parents) not telling us what you want."*

Death is Taboo

For many participants, the firstborn's lack of knowledge of a loved one's wishes was compounded by the shared belief in many families that "death" is a taboo subject. An African American woman and eldest daughter expressed frustration with her mother for not discussing her wishes: "*So, we never knew anything about the severity of her condition. I don't know if it was just a Southern thing that you don't communicate; you don't tell your*

family." Individuals who took on caretaker roles, especially if they were the eldest, felt that they could not broach the topic for fear others would perceive them as trying to hasten their loved one's death, *"Like you're trying to rush."*

EMOTION

Emotional Stress

Many firstborn children expressed a sense of being overwhelmed by having to make medical decisions for their parents and deal with filial conflict and tension that was seen as unavoidable. A firstborn Asian son, serving as a surrogate for his father reflected: *"I think it's one of the double-edged swords of having a close family… the person who does all the work has to bear all of that…the ones that don't do any of it, they're the biggest critics."*

Other firstborns discussed the emotional stress felt from a range of experiences including other family criticizing their judgment. A white man and eldest son who acted as a decision maker for his father stated: *"The person that does have to make the final decision - he's always going to hear about it and there's always going to be somebody to press the guilt on you."* Resigned to the pressure, a firstborn Asian son remarked, *"I didn't ask to be the oldest, you know."*

Loneliness

Participants also reported that sibling ties can be significantly affected when the parent becomes seriously ill. Because of this, the person taking on the brunt of the caregiving often described feeling unsupported and alone. An African American man and eldest son remarked, *"…everybody went away."* Many firstborn children and caregivers expressed a deep sense of loneliness, which added to their sense of burden and left many surrogates feeling scared and overwhelmed. The eldest Asian daughter who had cared for her father said tearfully: *"You can't even talk to no one…You carry a lot of weight on your shoulders."*

CONFLICT

Family Conflict

Only 3 participants reported making decisions as a family. These experiences were described as neither positive nor negative by 2 Latinas. Only 1 White man reported *"…it made it easier*." However, given unspoken filial roles, several participants spoke about family conflict and arguments including power struggles between older and younger siblings about specific decisions. Some firstborn participants expected a degree of understanding and deference from their younger siblings and expressed frustration when their siblings disagreed with their decisions and/or tried to get other family to side against them. One African American woman who had cared for her mother stated: *"My baby sister…she came in and turned into a different person…She didn't want her (mother) to leave…and tried to change their (other family) mind for them."*

Some younger siblings expressed resentment about the expectation that the eldest should make decisions, particularly when the firstborn was not the primary caregiver. A younger Asian daughter and primary caregiver described her frustration with transfer of the durable

power of attorney to her eldest sister: *"We got the do not resuscitate… Then they changed the power of attorney to my sister (the oldest) and so she gave the orders, but we did all the work."*

It was particularly disturbing to many younger siblings when the older sibling would decide to change the patient's prior medical preferences in spite of an established care plan. For instance, one African American younger sibling was angered over changes to burial plans: *"My mom wanted her funeral at one place; (then) they called someplace else and I lost it. Decisions that they were making, I would have never made them."*

Another Asian daughter caring for her parent was dismayed when her eldest sister decided to take over her father's decision making, despite not speaking to him for years: *"Whatever you plan doesn't take place because I'm not the oldest… 'The eldest has to be the one.' So she wanted it changed (the DNR order)…Then my older sister, she butt in."*

Solutions to Prevent Conflict

Many participants gave suggestions for dealing with family conflict and avoiding misunderstandings, such as having early discussions about individual's roles in decision making. A White older sibling explained how such discussions provoked arguments in his family, but that it helped clarify expectations ahead of time. Other firstborns and younger children found the best solution to prevent conflict and avoid the perception of monopolizing medical decisions while fulfilling filial expectations was to keep everyone in the family informed of any medical decisions. One Asian man stated, *"With my brothers now and my mom, I keep them involved…So they're not caught in the dark and all of a sudden says - you know, if you're the oldest - you get all the blame*."

In exploratory analysis, although no White or Latinos endorsed the theme of loneliness, all other subthemes were endorsed by all race/ethnic groups. Fewer White participants discussed filial expectations and death as taboo compared to other groups. In addition, fewer Whites and Latinosreported family conflict compared to African Americans or Asian/Pacific Islanders (Table 3).

DISCUSSION

To our knowledge, this is the first study of a racially and ethnically diverse sample that explored filial expectations and family dynamics related to birth order and surrogate decision making. In this study, a majority of participants from all racial/ethnic backgrounds included in our focus groups raised these issues unprompted.

Surrogate decision making for any loved one is often difficult and emotionally charged, and in prior qualitative studies has been shown to be isolating and overwhelming. [4, 7, 8] Studies in Asian cultures have found that firstborn sons naturally assume responsibility in decision making as influenced by traditional expectations of filial duty.[12, 27] Unique stressorscommon to firstborns from diverse cultures include filial burden, unspoken expectations, sibling conflict, and perceived family judgment.[12, 28-30]

Discussions of death is taboo in different cultures, including Asian[31] and African American[32], often leads to significant stress, a finding supported by our study. Furthermore, firstborn surrogates described how they went through this process alone, without the support of others, which further compounded their stress. At the same time, many younger siblings described feeling angry and powerless when their day-to-day caregiving and carefully chosen care plans were changed and overruled, not by an individual with more knowledge of the patient's preferences, but solely because of birth order.

In previous studies, preferences for family-centered decision making have been identified in multiple ethnic groups, including Japanese, South Asians, and Latinos. [12-14] However, some South Asians who value family-centered approaches to end-of-life decision making still prefer to have decisions made by a single family member because of concern of emotional burden on other family members. [12]Most participants in our sample felt that, in reality, the firstborn child would have the final say, even if other family members were involved. For firstborns, attempts at decision making as a family may, at times, create more conflict as our participants discussed issues related to power struggles and difference of opinions about what is in the patient's best interest.

Prior research has also indicated that relationships may be strained when several siblings attempt to make end of life decisions for an ailing elder. [33]This study echoes previous findings that contribute to conflict, such as differing care preferences and distrust between siblings providing the day-to-day caregiving versus those making medical decisions for the parent. We add to these findings by highlighting the power struggles that may occur between different siblings across diverse ethnic groups. Our results also provide some guidance for preventing conflict, such as having the parent discuss decision-making roles with all of their children early on. In addition, the firstborn (or the primary surrogate) can inform the rest of the family about the decision-making process and update the family frequently about the parent's medical condition. Finally, firstborn children can elicit and attempt to respect the opinions of primary caregivers who may be younger siblings. It may not be possible to change long-standing family dynamics, but good communication appears to have helped several of our participants minimize family conflict.

In exploratory analysis, compared to the other race/ethnic groups, fewer White participants endorsed all subthemes, and fewer Latinos endorsed family conflict. However, definitive conclusions about race/ethnic groups cannot be made from this qualitative study that did not formally ask about family dynamics. It may be that these subthemes are most prevalent among minority populations and Latinos and Whites experience less family conflict. It is also possible that Whites and Latinos maynot share information about family dynamics unless formally asked or only in one-on-one interviews. Finally, it may be that the different English-and Spanish-speaking moderators asked different follow-up questions related to family dynamics. However, differences by race/ethnicitywarrant further exploration.

These findings provide several important implications for clinicians. First, clinicians can help prepare diverse surrogates by asking patients about unspoken expectations of patients' firstborn children. Second, clinicians can help initiate or facilitate further discussions with the firstborn child. Third, clinicians can moderate discussions between the patient and

family about care preferences and the chosen surrogate, especially if the decision maker differs from the day-to-day caretaker. Finally, attention can be given to the specific needs of firstborn children when making medical decisions for a parent. Additional support should address potential psychological stress and family conflict.[34, 35]

Limitations

This study has some limitations. Participants were drawn from the same geographic location and may present a geographic bias in experiences of firstborn children and family dynamics. Although responses from a demographically diverse sample were elicited, factors such as acculturation to Western values, which has been associated with preferences for increased patient autonomy and decreased aggressive treatment at the end of life,[13, 36] were not evaluated. Additionally, length of time in the U.S. and generational status, which may have influenced perceptions of filial expectations, were not collected.

Conclusion

Firstborn children play a critical surrogate decision-making role in many different cultures, and often experience feelings of burden, emotional stress, loneliness, and family conflict. Because of these filial expectations, conflict may arise with younger siblings who may be the primary day-to-day caregiver. Clinicians should be aware of potential unspoken filial expectations for firstborns and help facilitate communication between the patient, surrogate, and extended family to reduce stress and conflict. Future research should explore race/ethnic differences in filial expectations and family dynamics in surrogate decision making.

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Table 1

Participant Characteristics, n=69

	Mean (SD), or n (%)
Age: Mean years ± SD (range)	69 ± 14 (33-89)
Gender: Female, n (%)	33 (48%)
Race/Ethnicity:	
White/Non-Hispanic, n (%)	18 (26%)
African American, n (%)	20 (29%)
Latino/Hispanic, n (%)	13 (19%)
Central American, n= 5	
Mexican, n=1	
South American, n=1	
Spanish, n=1	
Country of origin not specified, n=5	
Asian/Pacific Islander, n (%)	18 (26%)
Filipino, n=6	
Chinese, n=5	
Country of origin not specified, n=7	

Table 2

Overarching Themes Related to Firstborn Children in Surrogate Decision Making

Theme	Sibling	Race/ethnicity	Quote
Unspoken Expectations			
	Eldest daughter	Latina #3*	*"Because I'm the oldest, out of 8 kids, she put me in charge."*
	Younger daughter	African American #4	*"I'm the youngest, but I'm smarter than my brothers and sisters by a far shot, but see, when my mom was ill, my brother became executor of health and my sister for finances. I stood back. I wasn't going to fight them on anything."*
	Eldest son	Asian #18	*"The philosophy of the Asian people –the eldest in the family makes the decision. It doesn't have to be written down. It doesn't have to be pointed out. You can say, 'John Doe makes the decision.' And no matter what happens, whether you blame the person, male or female, that's the person that made the decision and it's in accord with the person that is dying. So that's it."*
	Son unknown birth order	White #48	*"The oldest one makes the decision. It's always the oldest."*
	Eldest daughter	Asian #37	*"Because in the past, you (her parents) didn't tell me that that will be happening, you know. 'You're oldest. You make the decisions.' But you're not telling us what you want. But you gave me this responsibility."*
Discussion of Death as Taboo			
	Eldest son	Asian #28	*"Yeah, the word 'dead' is not used at all. The oldest don't use that term. They prefer to use 'they left' or 'go' or 'they passed.'"*
	Eldest daughter	Africanerican #46	*"We didn't know till she was actually in the hospital and every time the physicians would come in, she'd ask that they…put us out of the room. So, we never knew anything about the severity of her condition. I don't know if it was just a Southern thing that you don't communicate; you don't tell, you know, your family."*
	Eldest daughter	Latina #36	*"It's difficult; nobody likes to talk about such bad things (death). I think that thinking about that, her defenses get lower. Because when an organism has stress or a person is tensed about something, their defenses get lower, they don't work in an efficient way."*
	Eldest son	Asian #33	*"My parents… they don't want to talk about graveyards, but I think it's something we should talk about. So I brought it to my mom's attention. 'Well, what? Are you telling me to go?' —I say, 'Well, that's not why, why I'm doing it.' —Like you're trying to rush."*
Emotional Stress			
	Eldest daughter	Asian #37	*"Yeah, my standing in the family, being the oldest, it's hard because some of my family lives in the Philippines. We have to look for a home for her (mother) and she don't want to and – being the eldest, they all said,' You can do it.' (take care of her mother at home) – but everyone got mad at me, you know, it's the family, other relatives, the friends, the neighbors. They said, 'You don't know what you're doing.'"*
	Younger son	Latino #27	*"The oldest daughter suffered a lot since she was in charge of him (her father). We gave all the responsibilities to her, because the mother was in the kitchen and I was working as well. It was very hard."*
	Eldest son	Asian #33	*"I think it's one of the double-edged swords of having a close family….because once relatives get involved, that's where it gets…in arguments. It's funny how the person who does all the work has to bear all of that. You know, and here the ones that don't do any of it, they're the biggest critics."*
	Eldest son	White #44	*"The person that does have to make the final decision, if he's going against another family member, he's always going to hear about it and there's always going to be somebody to press the guilt on you."*
	Eldest daughter	Asian #9	*"I didn't ask to be the oldest, you know."*
Feelings of Loneliness			

Theme	Sibling	Race/ethnicity	Quote
	Eldest son	African American #14	*"Yeah, like my momma, she was like the tree trunk or the whole tree. But when she had gotten to that state, the whole leaves start falling and drifting and the wind blew and everybody went away."*
	Eldest daughter	Asian #37	*"You can't even talk to no one, even to my family, especially if you are the oldest, too. You carry a lot of weight on your shoulders."*
Family Conflict			
	Eldest son	Asian #30	*"You know, the eldest one, the eldest son, has a kind of a family authority and the younger sibling, of course, should respect the elder's kind of decision making."*
	Eldest son	Latino #2	*"The doctor called my sister. Because I am the son…I told her (sister), "Don't touch her. Send her here with me and I will take care of her."*
	Eldest daughter	African American #41	*"My baby sister…she came in and turned into a different person. The woman dead almost. She didn't want her to leave…and tried to change their mind for them. We don't need that."*
	Eldest son	White #25	*"I had ten brothers and sisters. When my mother went, you never saw (such) a fight in your life (about her care)."*
	Younger daughter	Asian #21	*"We got the do not resuscitate…Then they changed the power of attorney to my sister (the oldest) and so she gave the orders, but we did all the work. I mean we cleaned his butt…we slept on the floor and we listened. At 3:00 AM, he'd wake up and he needed water and I'd give him water, but somebody else is giving the orders, but you're doing all the work."*
	Younger daughter	African American #4	*"My mom wanted her funeral at one place; (then) they called someplace else and I lost it. Decisions that they were making, I would have never made them."*
	Eldest daughter	Latina #36	*"In between sons or husbands or relatives, there are always discussions because one person wants to bury them somewhere, the other one doesn't … and that's a family problem."*
	Younger daughter	Asian #21	*"Whatever you plan doesn't take place because I'm not the oldest, but the other members did not really take care of him. Like my other sister didn't talk to him for six years…and then she popped in and she said,'You're not the oldest. The eldest has to be the one.' So she wanted it changed (the advance directive and DNR order). The doctor thought he actually had only two months. Then my older sister, she butt in."*
Potential Solutions to Prevent Conflict			
	Eldest son	White #44	*"If you start talking about it early, people get used to it and nobody wants to think about it, but it's easier to talk about it when it isn't inevitable than it is at a later date when it's getting closer. So it's better to start and talk about this when you're relatively young and get the kids used to the fact that it's coming."*
	Eldest daughter	African American #38	*"Someone passes and families sometimes fall apart -- bring everyone together. Everyone is there. Everyone heard mom say, 'My daughter's going to handle everything.' That's it. But if she needs input or your help, I know that you guys are here to support her decision*
	Younger daughter	Latino #35	*"The family has to get together to decide. Because sometimes there are conflicts in the family, because they say 'Oh they didn't tell me anything,' right? 'They didn't get my opinion or didn't ask me anything,' so it's better to get together and make a decision."*
	Eldest son	Asian #11	*"With my brothers now and my mom, I keep them involved. Even though I'm the closest proximity to her, you know, I can make the decision for her, but I let them know, you know, this is what we're going to do; this is what mom wants. So they're not caught in the dark and all of a sudden says - you know, if you're the oldest - you get all the blame."*

*Participant numbers were assigned at random. Illustrative quotes were obtained from 20 unique individuals. More than one illustrative quote was identified from 5 individuals.

Table 3

Themes by Race/Ethnicity Categories

Race/Ethnicity	Any Theme n (%)	Unspoken Expectation n (%)	Death is Taboo n (%)	Emotional Stress n (%)	Loneliness n (%)	Family Conflict n%	PotentialSolutions n (%)
White, n= 18	8 (44)	5 (28)	1 (6)	4 (22)	0 (0)	6 (33)	6 (33)
African American, n= 20	16 (80)	10 (56)	7 (39)	15 (83)	5 (28)	13 (72)	8 (44)
Latino, n= 13	10 (77)	6 (46)	3 (23)	6 (46)	0 (0)	3 (23)	6 (46)
Asian/Pacific Islander, n= 18	15 (83)	14 (70)	8 (40)	13 (65)	7 (35)	10 (50)	9 (45)