

case study

A Fifteen-Year-Old Translator

Mr. C is a fifty-eight-year-old Chinese immigrant. Late one Tuesday night he comes to the emergency room of a busy urban hospital complaining of severe chest and arm pain. The ER staff determine that he should be admitted to the cardiac unit for a full workup. Over the next several days he has a series of tests and is diagnosed with end-stage heart disease. His prognosis is poor and his lifespan is limited.

Mr. and Mrs. C arrived in the United States eight years ago. They speak almost no English, and rely on their three children to negotiate in situations where English is needed. Mr. C, the primary breadwinner, works long hours in a restaurant. His wife makes a little extra money as a part-time housekeeper. They have three children—two sons aged twenty-two and eighteen, and a fifteen-year-old daughter. The daughter is the most acculturated, is fluent in English, and attends a school for gifted children.

The daughter visits her father each day after school, while the sons come in the evening after work.

The C family does not have a regular physician. They have received most of their care at a local clinic. Dr. G, the attending cardiologist, does not know the family. She wants to tell Mr. C about the extent of his heart disease, the physical limitations he will encounter at home, and the adjustments he will have to make in terms of diet, medication regimen, and lifestyle. She also wants to present a range of treatment options, one of which involves a risky and complicated open-heart surgery. Dr. G will recommend that Mr. C give up his job, which involves carrying heavy trays and cleaning floors.

Because the hospital serves a large number of immigrants from many countries, a translation service has been put in place. However, there are frequently delays in obtaining a translator with the needed skills. When Dr. G calls

the hospital operator to request the help of a translator fluent in Cantonese, she is told that no Cantonese interpreter will be available until Monday morning, three days away. The cardiologist is reluctant to wait that long, as she herself is leaving for a week-long vacation the following day and she is uncertain that the covering cardiologist or house staff will be able to handle this case in her absence. Dr. G would prefer to meet with the family before then to give them this information.

During Mr. C's inpatient stay, Dr. G has observed the daughter, her devotion to her parents, and her close relationship with her brothers. In spite of being the youngest, she seems calm and mature. Even though the eldest son would traditionally take the leading role, she spontaneously takes the lead in most bedside discussions. Should Dr. G decide to use the C daughter as the interpreter rather than wait for the professional translator?

commentary

by Carol Levine

This case is not the kind that usually comes before a hospital ethics committee, excites passionate responses on a bioethics listserv, or interests a newspaper reporter. It might even be dismissed as uninteresting ethically. In its ordinariness, however, it raises serious questions about societal and professional responsibility, ethical obligations among family members, and social justice.

Immigration is still changing American society. Today's immigrants come with many of the same aspirations, determination, and problems as earlier generations. But they face a far more complex and unfamiliar health care system. Developing ways to bridge the gap between the culture of medicine and the patient's culture, whatever it may be, is a major challenge. "Cultural competence," broadly defined, is the ideal, but the reality in today's busy hospitals and clinics is more pragmatic: Is there anyone around who speaks this patient's language?

Most academic medical centers and

many community hospitals have staff or volunteers more or less fluent in another language, and some programs are more systematic. But this arrangement often fails. If the patient were a defendant in a trial, a competent adult translator would be provided. But in a hospital, where the patient's fate is equally at risk, there is no such guarantee.

Who is responsible for ensuring that patients receive clear information in language they can understand? The hospital? The medical and nursing professions? The government? Community-based organizations? By default, as in this case, it becomes the family's respon-

sibility, even though they are as much in need of clear information as the patient.

Within the family, as it was in earlier immigrant generations, the role of the intermediary with the outside world often falls to the younger members. They are more likely to have learned the language (not just English, but the various jargons they encounter). Depending on the situation, this role may help the young person gain maturity and responsibility or create heavy emotional and other burdens. In hospitals, all lay people enter alien territory. For young people acting as surrogates for parents or other relatives, the stakes are particularly high. Yet health care staff do not have time or inclination to look beyond the problem at hand. Often the role of translator is assigned by default to the young person most fluent in the language or most compliant with the request.

When chronic illness is involved, the potential conflicts become more complex. The young person may become not just a translator, but a caregiver. In this country we have become accustomed to thinking of family caregivers as middle-aged or elderly women, as so many are. But there is a large population of young caregivers—children, teenagers, and young men and women

in their twenties who have taken on major responsibilities for an ill or disabled family member. In the United Kingdom and Australia, these “young carers,” as they are called, are acknowledged in legislation, counted in censuses, and most important, served through special programs. In the United States, we are just beginning to acknowledge that they exist and have special needs.

While there are significant programmatic and policy barriers to identifying and serving young caregivers, perhaps the most difficult issues lie within the family itself. The obligations of family members to each other are powerful, whether they arise from love or duty or both. The tendency to close ranks in an illness and avoid outside help is strong, especially when the “help” is not offered by someone familiar with the family’s language and culture.

If outside help is not available or acceptable, the family must assign the caregiving tasks more or less equitably among its own members. But what counts as just in these cases? As political philosopher Susan Miller Okin pointed out in *Justice, Gender, and the Family*, philosophers have largely claimed that we should not subject associations based on blood and affection to scrutiny on grounds of justice. In her dissent, Okin

focuses on gender; women and the children for whom they care are the most vulnerable to inequities in family life. Yet, she claims, women should have equality within the family as much as they should outside it. Family life is a child’s introduction to justice, and a family should be just—that is, gender-neutral.

Should it also be age-neutral? Some parents make major sacrifices for their children. Should children be expected to do the same? How far should a family expect its young members to give up their own activities, opportunities, and future plans for the care of an ill older person? In immigrant families, traditional patterns of caregiving may conflict with contemporary mores. If the family has come to this country to give its children a better future, how does it balance this goal with the need for care? Are girls in such families doubly jeopardized—by gender and by age?

These are not questions to be resolved easily. In a just society, families should not have to sacrifice any of its members for the good of another. A combination of community support, appropriate services, and ongoing reevaluation are essential. We are nowhere near that ideal.

commentary

by Myra Glajchen

This case scenario is encountered all too frequently in major medical centers. Although the U.S. Office of Civil Rights has stated that every Medicare or Medicaid provider must provide language assistance to patients who need it, this service is often available only by telephone or through staff volunteers who are busy elsewhere when a request comes in.

This case raises a number of challenging issues in end of life care. First, is it appropriate to use a young family caregiver as translator when the medical situation is serious and a medically unschooled family member will have to de-

liver bad news? In fact, the consequences may be different for the patient and the newly appointed translator. Mr. C may feel isolated by his inability to communicate with the providers, but he might take comfort in having such news come from a trusted and loving family member rather than a stranger. Similarly, a translator might visit only once, or might participate over the telephone. On the other hand, this may pose a huge burden for the adolescent daughter, who must absorb this terrible news while simultaneously telling it to her parents and brothers.

It is also unclear what the consequences will be if the daughter assumes the role of interpreter. Will the C family press her for medical information and ask her to repeat the doctor’s recommendations following the family meeting?

Although she is fluent in English, she is not fluent in medical language. Will she be able to understand and communicate complex information about drugs, surgery, and other choices? Will the family follow the physician’s lead and place her in the role of decisionmaker as they discuss treatment options in the days ahead? The potential for error must also be recognized. A recent study found an average of thirty-one errors in medical interpretation in each clinical encounter, with errors of omission the most frequent type. In addition, most errors can have clinical consequences, and those committed by ad hoc interpreters—like Mr. C’s fifteen-year-old daughter—are significantly more likely to have clinical consequences than those committed by hospital interpreters.

Second, is it appropriate to appoint young family members as patient-provider intermediaries, without their consent, with little preparation, and in the absence of a comprehensive psychosocial assessment by a mental health expert? Although the cardiologist has formed an impression of the daughter, one could argue that she is not skilled in the area of developmental issues and family dynamics. Will the daughter have to give up school events and other activities to be on call as the translator? Is it fair to impose this responsibility on one so young?

commentary

by Francine Cournois

If Mr. C's daughter serves as an interpreter at the family meeting, this probably won't be the first time she assumes an important role on behalf of her father. Acculturated children of immigrant parents are repeatedly involved in helping their families negotiate important decisions, a task they may take on with considerable pride and pleasure. It is a myth that childhood is, or should be, only a carefree time. What is difficult about this situation is that Mr. C's daughter will be juggling three tasks: translating the content of what Dr. G is saying, serving as the bearer of bad news to her family, and coping with her own reactions.

The latter task is inevitable. At fifteen, Mr. C's daughter has the cognitive capacities of an adult. In addition, she is close to her family and intellectually gifted. It would be difficult or impossible, and almost certainly counter-productive, to hide the facts from her. When an adult avoids talking to a child about an obvious painful reality, it usually serves to protect the adult rather than the child. Mr. C is not returning to work, and each member of his family needs to adjust to his prognosis and the sudden shift in family members' responsibilities.

However, our medical system assigns the patient the right to share or conceal personal health information. By conven-

Third, in trying to balance the family's right to an objective translator with the physician's pressure to tell them the medical findings, whose needs are paramount? Ideally, the cardiologist should have handed the case to a trusted colleague who would impart the necessary information in the presence of the hospital translator. But in reality, hospitals are fast-paced environments and physicians are balancing multiple demands simultaneously. At the very least, the cardiologist could have given the C family the following option: "You can meet with Dr. X and an interpreter on Mon-

ing a family meeting to discuss the patient's diagnosis and treatment, Mr. C is being deprived of this right. From the perspective of current privacy rules, it seems essential to get Mr. C's permission for a family meeting and to offer him the choice of postponing the conversation until an interpreter can be found. It is also possible that there are available bilingual adults in Mr. C's life who are not family members and whom he would prefer to serve in this role

When it comes to ensuring the accurate communication of medical information, nothing can substitute perfectly for a physician who is fluent in the patient's language. Trained translators are the next best option. Untrained translators present more problems, and when they are family members, their feelings may make translating even more difficult. Yet it is important not to view any one meeting as the moment at which informed consent is given. Informed consent is a process, requiring multiple discussions, especially when the patient is being asked to understand a serious and complex disease. Even under the best of circumstances, patients can rarely recall all the information conveyed to them. A distressed patient may stop processing what is being said and feel paralyzed, unable to ask essential questions. Therefore, even if Dr. G goes ahead with her family meeting, with all of its possible pitfalls, she must still rely on her colleagues to review what Mr. C and his family understood and what questions they still have.

day, and we can review the options when I return from vacation, or we can have your daughter translate today, if she is willing to do so." In this scenario, the needs of both the patient and the daughter would have to be considered, to make sure the family does not pressure the daughter to take on this role. This would give the family more control over the manner in which they receive the medical information, and would allow them to preserve the roles of their family members as lay caregivers rather than translators.

We can imagine many changes and improvements in how Dr. G could act in this situation. But if Dr. G feels pressured for practical reasons to proceed with the plan she has devised, ask the daughter to be the interpreter, and conduct the family meeting, what is the best scenario we can construct?

It may be that the family will benefit from being together when Dr. G imparts her distressing news, and that they can use this forum to make plans and support one another at a time of crisis. The daughter's role as an interpreter does not prevent Mr. C's sons from asking clarifying questions, and all three children may be able to take turns in acquiring the information the family needs. Dr. G has an opportunity to offer psychological support to the entire family, and she may have concrete suggestions they can pursue, such as speaking to the social worker about disability benefits for Mr. C

No child wants to face early parental illness and loss; having to do so confronts the child with painful realities. But adversity also carries with it the possibility of growth, the discovery of heretofore unknown emotional reserves and competencies, an opportunity to take satisfaction in the caregiving role, and a chance to reflect on what is really important. While Dr. G may be drawing Mr. C's daughter into a confusing, even overwhelming role, we can still hope that the daughter will emerge a stronger and more determined person.