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A Map for the Journey:

Seeing Patients as People and as Your Customers

Judy Joyce

Do not assume that this customer has done research, comparison shopping, or insurance verification; that he or she understands that evaluation will take place first and that the organ is not waiting in the refrigerator; or that he or she even knows a transplant may be necessary in the future.

It is critical when addressing the intimate medical needs of patients to incorporate thoughtful planning that acknowledges and responds to the psychosocial impact of the transplant journey. This journey requires the direction, mapping, and participation of many team members. The medical team, the patient, the patient's family and friends, and even the community he or she lives in—all represent significant “co-travelers” on the trip of a transplant patient's lifetime.

Although we have always focused on those needing transplants as “the patients,” I would suggest that it is incumbent from a business perspective to begin to see these patients as individual people with distinct needs, perceptions, and resources. Indeed, they are your customers. It is very easy to be lulled into identifying the patient as someone with significant medical compromises who lacks clinical knowledge.

However, this person, the patient, is someone with a family affected by his or her organ failure. He or she may be an employee whose absence from the workplace is noticed, a parent whose children require parenting, an adult child whose elderly parents need caretaking, or a community activist whose projects and interests are waned by disease. Your patient might be a neighbor whose home was the center of life and fun, or a friend of many years' standing. The well-being of your patient is vitally significant to others.

This person is your customer, and without the willingness to entrust his or her medical care in your hands at your facility, there is no transplant program. Without his or her payor (insurance, state/federal program, state renal program), there is no reimbursement for your services. And without a good

experience on the transplant journey, your center may not be able to maintain its business, referral base, and the word-of-mouth marketing created by these valuable customers when they have been well served.

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From the very beginning, provide as much clinical information about the process as possible. At any given time, most patients and families absorb only a small amount of the data you provide, probably what is most closely connected to the portion of the continuum they are walking at that time. Repetition is healthy and establishes for your patient a road map of what is to come. Repetition is necessary if the patient and family are eventually going to absorb all of the vital information coming their way.

Coverage Information

Even though the customer is a subscriber with a payor(s) of some sort, all levels of insurance need to be verified for coverage of evaluation, living related donor costs, organ procurement costs, transplant surgery, outpatient immunosuppressants, lab work, and clinic visits. The possibility of coverage for air travel, lodging, and meal expenses should also be ascertained (though rarely covered). Air ambulance transport may also be necessary at some point. Follow-up care also needs to be determined, as well as who will provide it.

Although the patient will not always understand the importance of this financial information at this time, the medical caregivers should. It is the pa-

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tient's "medical bank account." He or she will need to know what level of protection is in his or her account at any given point in time.

Some centers create a generic binder that allows the individual facts of each customer's journey to be noted for reference. Such a journal might include an explanation of insurance terms such as deductible, copay, co-insurance responsibility, out-of-pocket, lifetime maximum, annual maximum, guaranteed renewable, health maintenance organization, preferred provider organization, Medicaid, Medicare, Medigap, and coordination of benefits. It is critical that those who will be depending on these multiple layers of reimbursement for the rest of their lives fully understand what is covered and what will be their own responsibility.

They must also understand that these coverage parameters can change, and will change, in the years to come. A binder or notebook containing the information just described can be a very useful, if not a critical, component of the transplant road-mapping process.

Financial Issues

Often the social worker and/or financial counselor have the initial encouraging and educational interactions with the patient. Although this can be rocky terrain, it is important for the patient to receive accurate information and to be taught how to access this same information himself or herself throughout the process. Many individuals have paid out-of-pocket for services and/or products for which they were unaware that they had coverage. Just learning that most insurance cards have telephone numbers and directions on the reverse side can be surprisingly useful in accessing information and healthcare appropriately.

Simply knowing what coverage they have, and whether it will suffice, can be of enormous comfort to a patient. When coverage is not sufficient, the clinical social worker can offer help in the early stages by identifying possible resources for necessary coverage. This team member can also assist the patient and family in working within the complicated governmental systems such as Medicaid and Medicare. Helping patients understand the difference between those two payors—and why they may be eligible for one but not the other—is critical.

The initial cost of transplant surgery can be overwhelming. In many cases, patients have coverage for those surgical expenses but have been affected by earlier costs of diminished health; loss of employment; or ongoing medical care due to diabetes, congestive heart failure, or other underlying disease. This may have already resulted in eligibility for Social Security disability and a loss of employment income. Thus, financial stress for this patient may also involve finding the money for air travel, lodging, and meal expenses.

Psychosocial Impact

It is not surprising that many transplant patients and their families experience financial crises, relationship issues, depression, and, at times, a loss of hope.

Skilled intervention by the medical team, and their clinical social worker specifically, can add much to diminish the negative impact, provide appropriate optimism, and maintain hope.

This area is not always valued as it should be, as it is not seen as a clearly clinical aspect of care. Yet, we know that the attitude, optimism, and realistic perspective of the patient and his or her family adds significantly to a successful outcome.

An "EASI" Formula

We are at the point where we begin to look at the patient as a person who is our customer from the very beginning. We will define what focus his or her care will require to provide the best possibility of success for the patient, which also amounts to success for the transplant center. Heightened **education**, **awareness**, **sensitivity**, and **intervention** will clearly ease the road for the patient and family as well as create a positive milieu for the transplant center.

Education

Although some may hesitate to completely inform patients of risks, education is the cornerstone of most worthwhile endeavors. Mortality and morbidity statistics, the difficult portions of the transplant continuum, their lifelong responsibilities, the risks inherent in surgery, medication side effects, and the reality of outcomes are topics that should be addressed as part of the service to the patient.

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Here it is best to include the “customer” in the fact-finding about your product, “the transplant,” so he or she can be better prepared for all eventualities that might await, including the fact that he or she may or may not be selected to be a transplant candidate.

This educational approach, although always well-advised, becomes essential at certain junctures. A patient deserves the facts regarding initial evaluations, decisions related to transplant status, and the wait for transplant. He or she may question the process of being called for possible transplantation, the intensive care unit (ICU) or transplant unit stay, discharge from hospital, follow-up care, and the “what if something happens” posttransplant phase.

There are many questions at each of these transitions. Appropriate brochures describing the course and what to expect are most useful and greatly appreciated. They also help diminish much of the panic patients sometimes experience.

- “What if I’m out of town when an organ becomes available for me?”
- “Will I ever have to go back on dialysis?”
- “But, someone has to die so I can live.”
- “What if an organ never comes for me?”
- “How much will it hurt?”
- “Will you tell me where my organ came from?”
- “How long will I be in the ICU?”
- “How will I know if my organ is rejecting?”
- “When can I go home?”

Even when your answer must be somewhat vague, it is a learning experience for the patient to recognize that not all concerns about transplant can be answered with precise information.

Although written information can provide an excellent reference, it is the face-to-face explanation from a trusted member of the medical team that infuses hope, belief, and optimism. It is also true that patients often do not know what to ask, or are uncomfortable “taking your time” or asking a “dumb question.” Thus, your team needs to meet the patient with the skillful ability to “pull the questions” or to volunteer the appropriate information as the continuum unfolds. Do not worry about being too repetitious, which, in the case of a trans-

plant patient, means repeating what the patient needs to remember.

The Wall Chart

Although the wall chart is necessary to monitor the patient’s progress, it is vital to remember the customer is in the bed and your eyes need to meet his or hers, as well as take in the chart on the wall. In subtle ways, patients can reveal many psychosocial issues that are not demonstrated on the chart.

Years ago, I greeted a patient who was awaiting a liver transplant: “How are you, Bill?” He looked at me from his ICU bed, jaundiced, rail thin, fatigued, and answered, “I’m going to die, Judy.” Knowing that he had been holding his own and that the medical team was hoping for a liver soon, I was concerned with his mental outlook. I asked if he had told the doctors of his fears. He answered quite simply, “Judy, you are the first one who has asked me how I am.”

Now, we know that scrutinizing the patient’s chart, listening at team conference, discussing test results, and getting feedback from the nursing staff enlightens the medical team about the status of the patient. Yet, we need to remember that the personal inquiry is worth much, often bringing out hidden fears, such as Bill’s. This intensely private anguish can then be immediately addressed.

Getting the patient to be comfortable sharing his or her critical perceptions is facilitated by teaching in lay language and interacting without a sense of rush or frustration and by honoring a patient’s history, strengths, and fears. It helps to answer difficult questions and repetitive questions with clarity. I knew a patient who wrote all of his questions down and taped them over the numbers on the wall chart—just so someone would take note that he had concerns. Indeed, they did.

Awareness

Awareness is critical to education. If the team doesn’t know what issues the patient is experiencing or what history he or she brings, that portion of education is lost, as are the benefits of adequate response. Matters such as poor vision, diminished hearing, illiteracy, language barriers, cultural issues, and religious beliefs are realities of patients’ lives and may reveal themselves subtly.

Many transplant centers recognize the traumatic effect of transitioning from home to a medical community in some far-away city for the transplant evaluation. For those whose critical condition requires them to stay as in-patients waiting for a transplant, this adjustment can be painful. A caregiver's awareness can allay fears associated with this situation.

Some centers have already incorporated a "family house" type of residence, which provides a reasonably priced, geographically acceptable home-like setting. The ability to interact with others who are walking a similar medical road can be supportive and educational. It is often quite efficient from the hospital's perspective as well. Patient and family members are easily located. Support groups, education, community resources, and activities are centralized, and processes are made more effective. In addition, the "community" becomes both active player and host, which enhances the personable atmosphere of the transplant center and the community it serves.

Conscious awareness enables caregivers to discover what other events might be occurring in the patient's life while he or she is going through the transplant continuum. The grief a patient displays may not be connected to the transplant at all. Perhaps this single mother had worked cleaning offices with only a 4th-grade education, so that her son, and now her daughter, could achieve a high school education and a graduation she will likely miss. For some, that may not be a highly significant event, but for this mother, it is. To provide the comfort she needs in the ICU, someone needs to understand that not witnessing the event in her family's life is breaking this woman's heart.

Sensitivity

Cultivating sensitivity educates the medical team about the patient and his or her family. Sensitivity begins with honoring the individual and the family that is his or her "core team." Creating relationships that engender trust, openness, and willingness to communicate builds a strong foundation for the competitive and high-speed roadways of healthcare today.

It does not take 2 hours a day to establish rapport. Looking someone in the eyes, taking his or her

hand, your tone of voice, candid answers, and genuine concern for the patient and his or her family are the cornerstones of a solid relationship. Taking note of, and commenting about, items in a patient's room can open doors to understanding and mutual respect. When such a level of relationship is established, intervention may be easier if it is required.

Interventions

During the continuum of transplant, there may be a need for various psychosocial interventions. These may cover financial issues, logistical problems, family stress, discharge arrangements, and other psychosocial events.

Financial Counseling

Intervention related to lack of financial support is very personal and difficult. Those without insurance coverage should be reminded that they have contributed throughout their own work life and tax history to provide social supports such as Medicare, Medicaid, and State Renal Programs. It is now not only their right but also their responsibility to make use of these resources. Although an individual may be clearly eligible for such a resource, many (especially those from the depression era) are staunchly resistant to these programs.

Your social worker and/or financial counselor can provide information on other resources, including

- Medicare
- Medicaid
- Medigap
- Qualified Medicare Beneficiary
- State Renal Programs
- State Pharmaceutical Programs
- High-Risk Insurance Pools
- Disease State Organizations
- Veterans Administration Benefits
- Pharmaceutical Manufacturers' Patient Assistance Programs
- Fundraising Options

Clarity about the newly legislated "lifetime" coverage for immunosuppressants through Medicare is important so transplant recipients can understand

if they will or will not be eligible. Awareness that an individual who is currently eligible for Medicaid may lose that coverage or incur a spend-down responsibility if he or she becomes eligible for Social Security benefits is also important. Recognizing that a patient who has excellent coverage at the time of the transplant through a COBRA policy will usually lose that coverage 18 months after the patient has left the workforce is crucial. Those patients eligible for COBRA coverage may not be able to access it because of unaffordable premiums.

Financial issues are highly important and go on for the patient's lifetime. Many immunosuppressant coverage issues surface a good time after transplant when providers terminate, or change.

Other Interventions

An intervention may cover a multitude of psychosocial issues. The following are just a few examples:

- A patient is intensely frightened of dying on the operating room table—just as her mother did 5 years ago. Intervention may include reviewing her mother's case, discussing issues specific to her mother in contrast to her case, education regarding anesthesia and length of surgery, and openness to other questions. Asking questions such as "How can we help you cope with this fear?" is helpful. Most often, the simple expressed concern and interest of the medical team allays a considerable portion of fear and allows the patient to continue forward.
- A transplant recipient's 16-year-old daughter is pregnant, and the husband is frightened of telling his wife because it might slow her recovery. However, help by reinforcing the patient's right to maintain her role of mother. The need to have her mother's input, awareness, direction, and support are vital components for the daughter, and also for the patient herself. In many such cases, the patient's spirits are usually buoyed by resuming a critical role in the family, despite the difficult situation.
- The family of a patient is overwhelmed by the question "what will we do?" when it is time for the patient to go home. A member of the team will need to accurately assess what the patient's needs will be at time of discharge. This may be significantly different from the patient's current needs at this time. Identification of family involvement, of community resources, medical equipment, and coping options will diminish the panic, which may affect patient and family. Although discharge is usually a long-awaited event, when it is close, there may be some approach/avoidance behavior, which is understandable. The patient has been in an extremely protected environment and is now going out into the "real world," which can be very frightening. Just knowing they are a telephone call away from assistance, and that they will be seen in the clinic on a daily/weekly basis, can be exactly the reassurance they need.
- A recipient presents at a clinic visit with a flat affect, reports feeling down, little motivation, can't concentrate, is having difficulty sleeping, and isn't sure why he had this transplant. After further assessment, it is determined that this individual is experiencing an episode of depression. The physician writes a prescription for antidepressant therapy and helps the patient decide whether some professional counseling might be helpful.
- A young father who had been employed as a field manager for a sales company is wondering if he can return to work. He has been on medical assistance for a number of years after his health no longer allowed him to remain in the workforce. Although he wants to work, he is concerned that he will lose his Medicaid health coverage if he earns a salary. The social worker is called to consult with this patient related to the process of returning to work and focusing on maintaining health coverage.

Goals of the Transplant Center

Most of the goals of the transplant center are clinical in nature. It is critical to identify and focus the team's efforts on a successful transplant for the ultimate customer—the person awaiting transplant as a second chance at life.

The short-term goal is to discharge this individual back into the community as soon as appropriate but also to maintain the recipient's state of well-being. If the recipient has been well served by the transplant center, it is often considered best that this

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individual will continue his or her long-term clinical service at the center. (There are times when this may be impossible, however, due to provider restrictions.)

From a business perspective, the transplant center wants its morbidity and mortality statistics to rank in excellence. This establishes a higher profile in the global transplant community, improving a center's fiscal standing and patient base through referrals and retention.

Investment in Organ Donation

It is critical to recognize the importance of the transplant center's involvement and investment in organ donation, both cadaveric and living related. Without this scarce commodity, those on transplant waiting lists will die and transplant centers will wither.

Thus, it is important that the center encourage media coverage of the miracle of transplant as it occurs at your center. The effort to keep public awareness high, to meet the needs of all the patients (customers) possible, requires close collaboration with others in the community. Centers need to collaborate with organ procurement organizations in their area to achieve as many positive outcomes on organ donation requests as possible.

Efforts directed toward internal sensitization and education of all healthcare professionals can have an immense impact. I attended a national transplant meeting several years ago when a cardiologist was asked to speak in the absence of a scheduled speaker on organ donation. When this medical doctor took the podium, he offered a startling personal insight. He acknowledged that in his work with cardiac patients, his focus had been on his tunnel view of his ability to treat and make well. He allowed that he had been shortsighted and had not advised, referred, or acquired agreement from his patients and/or their families regarding organ donation. This discussion with the audience awakened all of us to the intimate, internal need to sensitize, re-sensitize, and educate our colleagues about the opportunity we all have to contribute to the phenomenon of transplantation.

Finally, there eventually has to be a discussion within the center related to any "resistance" issues. In the real world, there always exists political, turf,

and general "lack of understanding" issues that stifle our ability to obtain as many organs as possible to save the lives of those we serve.

In 2000, a total of 22,827 organ transplants were performed, an increase of 5.4% over 1999 per the United Network for Organ Sharing (UNOS). However, this increase was more dramatic among living donors, who now compose nearly half of all organ donors. In 2000, there were 5532 living donors and 5984 cadaveric donors.

There is a growing effort to educate both the individuals awaiting transplant and their families, friends, and communities about the possibility of living-related donation. Those providing this service within a center understand the importance of sensitivity, delicacy, and intervention in approaching those who would like to donate, as well as those who are reluctant and uncomfortable with the subject. Waiting patients may have a very similar reluctance to accept an offered organ, and they too benefit from wise counseling.

Special attention to these critical tasks—and the possibility to which they each relate in their way—is a professional and awesome responsibility in today's transplant world.

Balancing Clinical, Business, and Humane Objectives

It is necessary to be alert to compromising decisions, which may limit the center's ability to provide the care it wishes to provide patients. This includes the difficult decisions about accepting contracts with lower, but possibly acceptable, reimbursement rates. With these diminished reimbursement rates and imposed restrictions, centers need to be willing to advocate strongly for appropriate patient care with all providers, including health maintenance organizations. Sometimes the most difficult task may be to relinquish patient care to the nephrologist or primary care physician when needed or required by insurance guidelines. While attending to these issues, it is also critical that the medical team remains sensitive to the financial impact of transplant on the patient/customer and his or her family.

Sharpen Your Tools

- In addition to providing an informative, patient-specific binder, identify pharmacy providers

that coordinate benefits, offer financial counseling, and educate patients about possible Medicare expiration for immunosuppressants.

- Create your own Medicare expiration program to advise patients proactively of possible pending Medicare expiration so that they may acquire immunosuppressant coverage through another resource if necessary.
- Hire specialized staff to handle pharmaceutical manufacturer patient-assistance program applications and follow-up.
- Encourage patient support groups. They go a long way in providing education, understanding, and direction to the transplant community.
- Mandate rotating physician, coordinator, financial counselor, and social worker atten-

dance. This visible attention and involvement will educate the medical team of ongoing and new problems/issues, which may be resolved.

- Ask the patient "How are you, really?" Wait for the answer.
- Listen to the patient's description of concerns.

Patients can provide clear direction and insight into the perception others have of your transplant center.

Replenish Yourself

Acknowledge your critical role in the miracle. Rest when you need to. Let your patients and staff know about your caring side. Rediscover and embrace the passion that brought you to this field in the first place, and don't let it go.