

# *Making Patient-centered Care Come Alive*

## *Achieving Full Integration of the Patient's Perspective*

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A patient-centered model of care has profound implications for the way that care is planned, delivered, and evaluated. Although most leaders in healthcare organizations today embrace the basic tenets of a patient-centered philosophy, they often find that moving toward a patient-centered model requires an unanticipated level of commitment and significant adjustments in organizational structures. In this article, the authors describe how patients and families have been integrated into the care delivery model by involving them in planning, decision-making, and improvement processes at all levels of the organization.

The idea of patient-centered care resonates particularly well with nurse executives and clinicians, who have long valued the central role of patients and families in the design and delivery of healthcare.<sup>1,2</sup> Yet even as most professionals in the healthcare arena

readily embrace a philosophy of patient-centered care, many underestimate the organizational commitment and related efforts associated with moving from a traditional organizational model to one that is truly patient centered.

At Dana-Farber Cancer Institute (DFCI) in Boston, we have been engaged for more than 5 years in a process of rethinking and redesigning many of our most critical operations in order to integrate the voices of patients and families into virtually everything we do. Although this work is far from complete, we believe we have made significant progress in crafting a new paradigm of care: one that places the patient and family in an entirely new position within the organization's operational and care structures.

The mechanism through which we have implemented many aspects of this new approach to care is the Patient and Family Advisory Council (PFAC). We currently have two councils: one for adult care and one for pediatric. By working through the councils, the voices of patients and families are blended with those of clinicians, administrators, and other staff as the processes and systems of care are designed and delivered. Patients provide input on organizational policies, are placed on continuous improvement teams, and are invited to join search committees and develop educational programming for staff. Members of the councils also sit on the Joint Committee on Quality Improvement and Risk Management, a board-level committee that approves the institute's quality improvement plan, evaluates outcomes of quality improvement activities, and reviews reports regarding sentinel events.

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Creating this level of integration requires important preliminary work within the organization. There must be a shared understanding of the critical components of patient-centered care. There must be strong advocacy for the concept at the highest levels of the administrative leadership team. And there must be in place a strong, interdisciplinary work team, for it is premature to think about integrating patients and families into a team if the underpinnings of effective teamwork are not yet in place.

Although individual organizations will come to these junctures in unique ways, there are themes in each organization's journey that provide important roadmaps for others undertaking such a venture. What follows is a description of the work at DFCI that preceded these developments, an overview of the critical concepts of patient-centered care that helped guide the process of change, and a discussion regarding the inner workings of the adult and pediatric advisory councils at DFCI.

## **Background**

In 1996, Dana-Farber Cancer Institute embarked on a joint venture with neighboring Brigham and Women's Hospital (BWH). The joint venture was focused on merging cancer care services at the institutions into a single program that would eventually be called the Dana-Farber/Brigham and Women's Cancer Center. As part of the joint venture, all adult inpatient services would be moved to BWH, and most adult ambulatory services to DFCI. (DFCI and the Children's Hospital of Boston had already implemented a similar care delivery model for pediatric cancer services.) As patients at DFCI and BWH became aware of the joint venture, they voiced anger and concern about its potential impact on the quality of care.

Importantly, these issues were being raised at a time when public trust in DFCI was already being tested. Earlier in the year, two medication errors at DFCI resulted in the death of one patient and the serious injury of another. The organization's response—which helped set the stage for a new relationship with patients—included looking deeply into the philosophy, systems, and structures that guided the way it provided care.<sup>3</sup> Like most organizations, DFCI had prided itself on its relationship with its patients and families and felt itself to be truly patient- and family-centered. However, the dual tragedies fostered the development of a profoundly new level of awareness about the unique insights that patients and families can bring to organizational decision-making.

Thus sensitized to the need to listen and respond to patient concerns, DFCI administrators actively sought to ensure that the voices of patients and families would be heard as the joint venture moved forward. Working with their colleagues at BWH, they invited interested patients and family members to join committees planning the new ambulatory services and the inpatient move. Initially, staff on these committees worried that including patients and family members would inhibit open discussion and undermine the planning process. Their concerns were laid to rest, however, as they witnessed the role patients and family members could play in resolving problems associated with each initiative. After several meetings, staff began to respect their new colleagues and accept them as full partners in the planning process.

Active involvement of patients and family members helped to change the tone and focus of the dialogue between the institutions and their patients. Communication that had focused in part on responding to angry patients instead became a dialogue that engaged patients as partners in the problem-solving process. Appreciation for the contributions of patients and families was formally expressed during the opening ceremonies for the new inpatient unit at BWH, when patients and family members who had served on the committees cut the ribbon.

Recognizing the benefits gained by involving patients and families in the joint venture planning process, DFCI subsequently began working to capture the patient's perspective at every level of decision-making and to incorporate that perspective into organizational policies and actions. After integration of the inpatient and ambulatory units was complete, DFCI and Brigham and Women's established a permanent adult patient and family advisory council.<sup>4</sup> Not long afterward, DFCI worked with Children's Hospital, which had developed a patient and family council in 1985 that advised on their overall pediatric mission, to develop a council that focused exclusively on pediatric cancer care. As DFCI began the move toward increased patient and family involvement, it was crucial for its leadership team to become champions of this new model within the organization.

## **The Importance of Executive Leadership**

Changing the paradigm of care to a patient-centered model is a significant shift that requires the leadership and involvement of the senior executive team. The executive team sets the tone for the organiza-

tion, makes change a priority, and sanctions structures essential to the implementation of a new model. Because a patient-centered model touches every part of the organization, leaders representing care providers and supportive personnel from each area must be involved in the change process.<sup>5</sup>

The senior executive in Patient Care Services faces a particularly strong mandate for leadership in this regard. Direct patient care and daily interaction with patients and families defines the work of the clinical disciplines in Patient Care Services. An effective patient-centered model cannot be designed or implemented unless the executive leading these disciplines plays a lead role.

As part of the process of change, the senior executive team must develop a shared understanding of the meaning and goals of patient-centered care and foster understanding among others in the organization.

### *Patient-centered Care: Overview*

A patient-centered model of care is based on mutually beneficial partnerships among healthcare providers, patients, and families and has profound implications for the planning, delivery, and evaluation of care.<sup>6</sup> It is significantly different from the classic biomedical model of care. Traditionally, care has been organized around the needs and desires of healthcare professionals, particularly physicians. Although the centrality of patients and families seems understood as a basic tenet of healthcare, restructuring organizations around the needs of patients and families in fact will challenge most hospital-based organizations to significantly change a long-existing culture.

A patient-centered approach has been cited as a way to achieve both higher levels of quality and increased patient satisfaction. Two recent reports from the Institute of Medicine strongly recommend a patient-centered approach, noting that patients' sense of control and perceived quality of life are favorably impacted by involvement in their care.<sup>7,8</sup> In their book, *Through the Patient's Eyes*, Gerteis et al<sup>9</sup> make similar recommendations and describe the importance of listening to patients and families. Drawing on extensive interviews, they affirm that patients want to be more integrally involved in decisions related to their care.

Patient-centered care has been linked to effective team performance, which can, in turn, have a positive impact on quality. The safety literature highlights the value of highly collaborative teams and

links them to error reduction and effective performance in settings as diverse as the cockpit and the operating room.<sup>10</sup> A recent Institute of Medicine report on patient safety in healthcare also underscores the value of effective teams.<sup>11</sup> The report notes that efforts to develop safe care practices must all be based on one common element: building consensus among multidisciplinary, high-performing teams in which communication, collaboration, transparency, and joint decision-making occur.

Arguably, when teams expand to include the "customers" of the service, one would expect them to become more customer focused in their decision-making, more proactive about patient problems, and more effective in working together. These assumptions underlie, in part, the push for patient-centered care.<sup>12-14</sup>

### *Defining and Implementing Patient-centered Care*

At DFCI, we view the patient as an individual, with individual needs and preferences, and as a member of a family unit. Just as the patient and the family are involved in the process of care, they are also included in our definition of patient-centered care.

A patient-centered model of care has implications for every aspect of clinical practice and organizational structure. When developed to its fullest extent, it should help define how patients, families, and providers interact at the individual level, how clinical services are structured, how ambulatory units are designed, how bills are formatted, and how buildings are maintained.

Making the patient and family an integral part of the healthcare team is a leap from the more traditional and, in some ways, more comfortable methods with which we have involved patients in the past. For example, although satisfaction surveys and focus groups can give patients a way to voice specific concerns or opinions, they often fall short of providing ongoing, real-time patient feedback into organizational strategies and initiatives, and usually fail to achieve the goal of involving patients in the process of care. Organizations that rely solely on these snapshots of patient input often find themselves struggling to discern how patients feel about specific aspects of the organization and about the organization's attempts to improve. Patient- and family-centered models need to move beyond the one-dimensional approach, and instead provide opportunities for ongoing and direct patient input into the workings of the organization.<sup>4</sup>

Pediatric programs have been among the first to incorporate principles of patient- or family-centered care. Johnson cites several pediatric organizations that began by adopting elements of a patient- and family-centered model into the design and operations of a few select units. In other cases organizations developed patient or family committees to advise on particular projects or on broad institutional policies.<sup>6,15</sup>

By necessity, organizations typically narrow their scope in this way at the start and identify areas for initial implementation that will help them articulate the meaning of patient-centered care within their organization. This was our experience, as we initially formed a patient work group with a distinct function in mind: namely, helping us ensure that our patients and families retained or regained confidence in our organization as we entered into the joint venture with BWH. However, had we limited our vision to how patients and families could be involved in these activities, it is unlikely that our model would have evolved beyond the work at hand. Rather, this initial, more limited involvement served as a springboard to incorporating the patient and family as fully functioning members of our team.

### ***The Structure of the DFCI Patient and Family Advisory Councils***

Our adult and pediatric councils were formed as permanent organizational structures in 1997 and 1999, respectively. The overall charge to the councils is to provide ongoing input on patient care, program planning, and organizational priorities and decision-making within the adult and pediatric cancer centers. The councils are each comprised of up to 15 patients and family members and several cancer center staff. Patients and family members on the councils commit to a 1-year term, which they can renew for up to 3 years. After their full term is over, members can choose to continue as associate members or to resign from the council.<sup>4</sup> Cancer center staff who are on the councils include the Senior Vice President for Patient Care Services at DFCI, the Vice Chairs of Adult and Pediatric Oncology, and representatives from quality improvement, social work, and other departments that interface routinely with patients. The staff attend council meetings and share voting privileges with council members.

Two patients or family members from each council serve as council co-chairs, running each meeting and ensuring appropriate follow-up on agenda items. Each council also has a staff liaison

charged with linking the councils into the organization. The staff liaison works with the council to define its role within the cancer center and with cancer center leadership and staff to identify issues and initiatives that should be brought to the council. The staff liaison also coordinates efforts to involve council members on institutional committees, work teams, and other structures.

The staff liaison is appointed by DFCI's Senior Vice President for Patient Care Services, who provides oversight on the efforts to integrate the councils into the organization's activities. Senior leaders whose work brings them into contact with patient concerns (such as social workers, nurse managers, and directors and staff in quality improvement) are ideal candidates for the staff liaison role, given their intimate knowledge of organizational strategy and operations and their experience in working with patients, family members, clinicians, and administrators.

### ***Selecting Council Members***

Initially, several adult council members were drawn from patients and families involved in the joint venture working group. In addition, early members of both councils included individuals who had previously provided input on other DFCI activities or who had offered suggestions for improving the care they or their family members received. Currently, potential new members are recruited through outreach efforts conducted by sitting council members. For example, the opportunity to sit on the councils is regularly featured in the council newsletter, "Side by Side," which is authored by a council member and mailed to members of the cancer center community, which includes more than 700 patients and family members.

Recommendations from the Institute for Family-Centered Care have been useful in guiding member selection.<sup>15</sup> In general, we look for individuals who are experienced in collaborating with professionals and with members of the broader community and who are comfortable expressing their opinion in a group and listening to the opinions of others. Although we want members to be enthusiastic about the cancer center and its mission, we also want them to be able to stand back, view the center critically, and express criticisms and suggestions constructively.<sup>4</sup> The ideal candidate demonstrates a willingness and an ability to work as an active partner with cancer center staff and providers.

Potential members are interviewed by a member of the council and by the council's staff liaison.



During the interviews, we try to determine whether the interested patients or family members are concerned not only with their own personal experiences but also with the broader organizational issues and the experiences of other patients and families. We discuss the roles and responsibilities of council membership in detail and work with the candidates to determine whether they will be able to meet the council's demands on their time and energy.

When the councils were first formed, a great deal of effort went into recruiting, selecting, and mentoring new council members. Council members who had worked on the joint venture and who understood the meaning and importance of actively partnering with staff spent considerable time coaching new participants. Today, sitting council members continue to mentor new members, helping them to acquire a deeper understanding about the workings of the organization and the role and responsibilities of the advisory council.

### **Council Meetings**

Each council meets monthly for 2 to 3 hours. Meeting agendas are established by the council co-chairs and staff liaison, and include items suggested by council members or proposed by cancer center staff. In addition to participating on the council, members also participate on council subcommittees that focus on particular aspects of council activity, such as communications, recruitment, and special council initiatives. Subcommittee meetings are typically incorporated into the general meeting's time slot.

Over time, the adult and pediatric councils have led a variety of initiatives focused on specific issues affecting adult and pediatric patients. In addition, members of the councils have been asked to sit on a broad range of institutional work teams and committees, thus expanding the councils' reach and impact within the organization.

### **Special Initiatives**

One of the most exciting aspects of our new relationship with patients and families is being able to facilitate and witness patient-generated initiatives that are designed to improve care (Figure 1).

Our early experiences with the joint venture working committees were particularly instructive in this regard. Patients and family members participating on these committees played a key role in designing the new ambulatory space and in ensuring

Teen needs survey
Publication of council newsletter ( <i>Side by Side</i> )
Study of unplanned admissions for neutropenic patients
Study of emergency room visits by pediatric patients
Study of wait time in outpatient clinics
Patient rounds
Educational program for first year oncology fellows

Figure 1. A subset of adult and pediatric council initiatives.

a smooth transfer of patients from DFCI to BWH. Their involvement continued after planning was complete. On the day of the inpatient move, they helped transfer patients and equipment from DFCI to the new inpatient unit. After the move, they reviewed patient satisfaction data and conducted "rounds" during which they interviewed patients about their transfer experience and about their inpatient care. In conjunction with the inpatient nurse manager and nursing staff, council members reviewed their findings and designed ways to decrease patient anxiety and confusion associated with the move.

Today, council members continue to conduct patient rounds. These rounds benefit patients, who typically welcome the chance to speak with another person who is living with cancer. The rounds also benefit the organization, because patients often use them as an opportunity to offer suggestions for improvements in care at the cancer center.<sup>4</sup>

Our adult council has also developed and implemented an educational program for first-year oncology fellows. Over dinner, council members engage the fellows in conversation about the cancer patient's experience. With direction and support from the director of the psychosocial oncology service, the group provides a forum where patients and fellows can interact and share comments, anxieties, or concerns about the relationship between physicians and their patients and families.

PFAC initiatives have also examined specific aspects of cancer center operations. For example, through conversations with patients, adult council members learned that patients with neutropenia who were admitted after office hours often experienced long waits in the emergency department. These waits were not only exhausting but also delayed the start of treatment. Working through the council liaison, the PFAC formed a work team that included council members, nurses, physicians, and

staff from admitting, medical records, and the emergency department. Together, the team analyzed patient satisfaction data, patient flow, and other factors associated with the admissions process. Their work resulted in recommendations for a modified process that involved using the telephone to screen patients at home and then directly admitting selected patients to the inpatient units, bypassing the emergency department altogether.<sup>4</sup>

Similarly, the pediatric council initiated a project examining the experiences of children brought to the emergency department. After careful study, the council recommended that pediatric oncology patients should be triaged directly into treatment rooms, thus avoiding a long wait and potential exposure to infection in the waiting area. Emergency department staff accepted the council's suggestion and worked with the council to design and implement a new "ED Fast Track" system that has eliminated wait times and yielded increased satisfaction among oncology patients and their families.

### ***Participation on Cancer Center Teams and Committees***

Cancer center staff, unused to collaborating with patients and family members on operational issues, were initially reluctant to involve members of the councils in planning and program development activities. However, staff who interacted with the councils soon began to realize the value of including patient and family representatives in a broad range of institutional initiatives. Soon after the councils were formed, the organization began to ask council members to participate on cancer center work teams and improvement initiatives. Council members joined staff in space planning, on search committees, and on improvement work teams. Council members have also participated in visits from accreditation agencies and, most recently, have joined the Multidisciplinary Lead Team, a high-level steering group that is overseeing multiple improvement initiatives focused on improving care in the ambulatory units.

Patient and family involvement is now an expectation rather than an exception, and members of both councils sit on an increasing number of standing committees (Figure 2). By participating in these groups, council members have a voice in setting organizational policies and in monitoring and guiding operations. For example, PFAC members sit on the adult and pediatric Clinical Services Committees, which set standards for inpatient and outpatient

<p><b>Ad hoc groups</b>  Search committees  Pediatric clinic renovation planning  Radiology renovation planning</p> <p><b>Improvement initiatives and workteams</b>  Medical records availability  Chemo turnaround time  Multidisciplinary Lead Team (overseeing multiple ambulatory improvement initiatives)  Inpatient Care Improvement Team</p> <p><b>Committees</b>  DFCI-BWH Adult Oncology Clinical Services Committee  DFCI-Children's Hospital Pediatric Oncology Clinical Services Committee  Nursing and Patient Care Services Leadership Group  DFCI's Joint Quality Improvement and Risk Management Committee</p>
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Figure 2. A sampling of cancer center committees and work teams that include council members.

care. Even more significantly, PFAC representatives also attend quarterly meetings of DFCI's Joint Quality Improvement and Risk Management Committee. This board-level committee is mandated by the Board of Medicine and is composed of senior members of the organization. During its meetings, the committee reviews DFCI's annual quality improvement plan and the results of improvement activities reported by the Medical Staff Executive Committee, the Executive Committee for Research, and the Executive Management Group. The committee also reviews reports regarding sentinel events within the organization.

As members of organizational work teams and committees, PFAC members face the same expectations as other DFCI staff for protecting patient confidentiality. Similarly, council members on these committees are asked to demonstrate objectivity and discretion as they work across organizational boundaries. When PFAC members are appointed to committees, they are oriented by senior clinical and administrative staff and periodically receive additional off-line coaching and support.

Maintaining a patient and family council and having council members participate in a broad range of institutional activities inevitably entails some costs. Upon careful consideration, we believe that the benefits associated with this work far outweigh the costs that we incur.

## **Resource Requirements**

Resources associated with maintaining the adult and pediatric councils include the time that cancer center staff spend on supporting the councils and participating in PFAC activities, expenses associated with publishing the council newsletter and other publications, and incidental support for council initiatives. Currently, one full-time administrative assistant is dedicated to supporting the councils. In addition, the council liaison and other DFCI staff spend a combined total of 8 to 12 hours each week working to ensure council integration into institutional activities. At this point, however, work to integrate the councils into cancer center initiatives is seen as a part of normal business and is folded into routine efforts to ensure a representative, multidisciplinary approach to planning and operations.

Patients and family members on the councils also invest a significant amount of time in council activities. For many, the monthly meetings represent just a portion of their investment, and they commit an additional 10 to 15 hours per month to committees and work teams. As noted above, potential members must understand the time demands associated with participating on the PFAC and should be screened for their ability and willingness to make such an investment.

## **Discussion**

When the adult and pediatric councils were first established, DFCI's leadership team hoped they would provide ongoing and detailed information about patient satisfaction, preferences, and recommendations. Leaders also hoped the councils would help to reassure patients about the cancer center's commitment to patients and families and improve patient-provider collaboration. But few at DFCI anticipated how the councils would evolve to become an integral part of organizational decision-making and an important component of quality patient care.

Our lessons learned have been many and valuable, and are discussed in the following sections.

### **Collaboration and Trust as Prerequisites**

Bringing patients and family members into an institution's decision-making processes and onto organizational work teams requires a level of trust and mutual respect between patients and providers that goes beyond that encountered in the typical provider/patient relationship. Such trust typically develops over time, as council members and staff work side-by-side to understand and address institutional problems. Before patients can be brought into deci-

sion-making roles, however, the leaders and staff within the organization must themselves operate with a high degree of mutual respect and trust.

At DFCI, trust was forged among the leadership team and between administrators and clinicians by a process of introspection and self-examination that resulted from two serious medication errors. Ironically, the errors prompted not only the development of new and better medication administration systems, but also the development of more open communication and effective collaboration at all levels.

### **The Benefits of Full Disclosure**

As patients and families participate on work teams and committees, they are inevitably exposed to organizational problems and missteps. At first, such disclosure may seem threatening. Many healthcare organizations are inclined to avoid discussing potentially harmful incidents with patients unless a lawyer is present or unless the discussion occurs within the context of risk management or litigation activities.

Certainly, the issues of disclosure and perceived organizational vulnerability must be raised before patients and family members are brought in as members of the team. We have found that the benefits of patient and family involvement far outweigh the risks. For us, viewing the patient as a partner rather than as a potential adversary has resulted in more open patient-provider communication, earlier identification of potential problems, and development of more effective solutions.

### **Engendering Patient Commitment**

Before an organization can begin to include patients and family members in institutional efforts, it must have a dedicated and committed community of patients. Our efforts to develop the PFAC may have been eased by the strong relationships that we, as a cancer center, inevitably have with our patients. Relationships between cancer care providers and patients are often long term and marked by an unusual level of intensity and intimacy.<sup>16,17</sup> In many ways, however, we are no different from other healthcare providers, who also have populations of patients who require extended or repeated care and with whom they develop a strong bond. Patients and family members affected by heart disease, diabetes, neuromuscular disorders, mental illness, and other chronic conditions can offer a unique perspective on care and treatment and may be candidates for participation in patient-centered efforts. Patients who experience a short-term relationship with a provider may also be interested in broader participation in or-

ganizational activity, and can frequently offer insights into the organization's image and operations.

### **PFAC Impact on the Patient-provider Relationship**

Perhaps inevitably, the adult and pediatric councils and broader patient and family participation have impacted the patient-provider relationship at our organization. Patients and family members are now partnering with cancer center staff on issues that were previously restricted to clinicians and administrative staff. One consequence of patient involvement has been the development of a greater sense of equality in the patient-provider relationship at the level of direct patient care.

Nurses, physicians, and other clinicians tell us that when working with a patient or family member, they often consider whether the individual would be interested in participating on the adult or pediatric council. Such consideration reminds the clinicians that patients and family members are partners in institutional and program planning, and changes the way staff perceive and work with the patient. Similarly, patients and family members who participate on a council have reported a new level of provider-patient collaboration. They begin to realize they are not beholden to clinicians but instead can play an active role in their own care planning.

### **The Importance of Strategic Planning**

When we set about the work of formalizing our councils, we were committed to a well-conceived set of goals and expectations. As we proceeded with each step of the process, there was ongoing attention to the unique cultures within our organizations and to how the work was progressing. This process of reflection allowed us to evaluate the work in an ongoing way and to plan needed change accordingly. We believe that this careful attention to process accounts in large part for our ultimate success. A venture such as this is bound to be at best ineffective, and at worst destructive, if a less careful, quick-fix approach is taken.

### **Remaining Challenges**

Our work in developing a patient- and family-centered model of care is not complete. We have found

that in many ways, developing such a model is a journey. As we reach one destination, our understanding of what it means to be patient and family centered deepens and new opportunities for patient and family involvement are revealed.

For example, during the past year, we have focused as an organization on ensuring that minorities have equal access to clinical trials. As council members became involved in discussions about this issue, they recognized that the councils also do not adequately reflect the broad range of minorities served by the adult and pediatric cancer centers. As a result, both councils have begun work to recruit a more representative mix of patients and family members for participation.

A larger challenge relates to how our organization can more fully bring the concepts of collaboration, shared decision-making, and partnership to the individual patient-provider relationship. To our advantage, we find that our clinicians, who embrace these concepts philosophically, welcome the chance to include patients and family members in our efforts to reshape aspects of day-to-day care so that it becomes even more patient and family centered.

### **Conclusion**

We believe that our work with the adult and pediatric councils has enabled us to begin to define an entirely new approach to care: one that truly places the patient and family at the center of our mission, at the center of our organization, at the center of our systems, and at the center of every individual clinician/patient encounter. As we go forward, we plan to study more rigorously and quantify the impact of our patient- and family-centered model on patients and staff. We hope that others will benefit from our experience, and will join us in finding new ways to incorporate the voices of patients and families into the design and delivery of healthcare.

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