

# Fragmented care and whole-person illness: Decision-making for people with chronic end-stage kidney disease

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## Abstract

**Purpose:** The study reported herein sought to better understand how patients with multi-morbid, chronic illness—who receive care in institutions designed for treatment of acute illness—experience and engage in health-related decisions.

**Methods:** In an urban Canadian teaching hospital, we studied the interactions of six hemodialysis patients and 11 of the health professionals involved in their care. For 1 year (September 2009 to September 2010), we conducted ethnographic observation and interviews of six cases each comprising one hemodialysis patient and various health professionals including medical specialists, nurses, a social worker, and a dietician.

**Results:** We found that the ubiquity and complexity of health-related decision-making in the lives of these patients suggests the need for a more holistic interpretation of health-related decision-making.

**Discussion:** We propose an interpretation of decision-making as an ongoing process of integrating illness and life; as frequently open-ended, cumulative, and relational; and as fundamentally shaped by the fragmented delivery of care for patients with multiple morbidities.

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**Conclusion:** Our understanding of decision-making suggests that people living with complex chronic illness need to receive care from institutions that recognize and address their multi-morbidity as a whole illness that is constantly being integrated into the life of a whole person.

## Keywords

Co-morbidity, fragmented care, decision-making, whole-person care

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## Background

Caring for the growing number of people with chronic co-morbid illness<sup>1</sup> poses particular challenges to health care institutions. For patients with end-stage renal disease (ESRD), care is particularly complex because co-morbidity is so common, vulnerability to infection is high, and hospitalization and death are frequent. In an earlier study, we found that of the 300 dialysis patients served in one urban teaching hospital, 3% were hospitalized at any one time and 15–20% died each year.<sup>2</sup> The challenge of responding well to the needs of this population can be explained in large part by the organization of health care institutions according to distinct disease categories. For example, ESRD patients with diabetes and heart disease—two common co-morbidities—receive care from three different specialists, in separate clinical settings, each with distinct clinical guidelines.

Most decision-making related to ESRD occurs in such a context, one that is increasingly acknowledged as providing “fragmented care”.<sup>3,4</sup> Tinetti et al.<sup>5</sup> warn of the potential harms that can ensue from treating a single disease in the context of multi-morbidity, and argue for decision-making that integrates patients’ risks, co-existing conditions, and care goals.

In the social sciences literatures, health-related decision-making in the context of chronic illness is conceptualized as a

complex process with characteristics and outcomes that differ radically from decision-making for acute care purposes.<sup>6</sup> Decision-making for chronic illness is distributed both within and beyond the care institution, reversible, revisited, relational, both intuitive and deliberative, and has ongoing and changing implications for the lifestyle of both the patient and the family.<sup>6–8</sup>

In contrast, many studies in the clinical-practice and health-services literature seem to assume a shared understanding of decision-making as occurring within individuals, generally in the patient–physician dyad, on isolable topics, and at specific moments in time. In the context of ESRD, the majority of this literature focuses on choice of treatment modality<sup>9–13</sup> and end-of-life decision-making including conservative care and the role of advance care planning and advance directives.<sup>14–17</sup> More recently, increasing attention has been paid to the ethical challenges of and need for realistic communication with patients (particularly the elderly) and families about survival rates and quality of life with renal therapy.<sup>15,18,19</sup>

A largely separate literature on self-care and self-management, uses terminology such as self-efficacy, adherence, and lifestyle choices to characterize ESRD patients’ daily illness-management activities;<sup>20–22</sup> and much attention is paid to educational programs and other interventions to support patients in overcoming barriers to better

self-management.<sup>23–25</sup> The apparent delineation in these practice-based literatures—between medical and self-care decision-making—suggests that these two kinds of decision-making are considered by some to be distinct and separable, and we question the pertinence of this delineation for patients with chronic, co-morbid illness. Moreover, we believe that an interpretation of decision-making as socially embedded is more useful for understanding how people living with chronic kidney failure engage in health-related decision-making and how that decision-making is shaped by the fragmented nature of the acute-care settings in which they spend so much time.

## Methodology

Ethnography guided the overall design and orientation of this study. Rooted in cultural anthropology, ethnography seeks to understand human behavior in the context in which it is embedded.<sup>26</sup> While its uptake in a wide range of disciplines has contributed to variation in ethnographic approaches, ethnography is generally understood to be characterized by certain key features: (a) attending to taken-for-granted beliefs and practices of everyday life, (b) gaining an insider perspective on these beliefs and practices over a relatively long period of time, (c) achieving multiple insider perspectives based on a variety of data sources and data-collection methods, and (d) interpreting beliefs and practices as shaped by and dependent on the context in which they occur. “It is arguably the way in which ethnography makes links between the micro and macro, between everyday action or interaction and wider cultural formations through its emphasis on *context*, that most clearly distinguishes ethnography from other approaches (and makes it particularly valuable for researching healthcare issues)” (Savage,<sup>27</sup> original emphasis). Through this approach, we were able to conduct an

in-depth analysis of the micro-world of decision-making and describe the macro-context of health care in which decision-making occurs.

## Setting

Our ethnographic study was conducted in an outpatient dialysis clinic of a tertiary care teaching hospital in a large, culturally diverse city in Canada. The unit provides dialysis service to approximately 150 patients with a staff of approximately 40 nurses, five nephrologists, one nurse practitioner, one dietician, and one half-time social worker.

## Participants and recruitment

With approval from the Ethical Review Board and in consultation with a collaborating nephrologist and nurse practitioner, we identified six co-morbid ESRD patients who represented a wide range of ages, illness histories, and experience with hemodialysis. This purposive sampling ensured access to a rich range of care-related communication and decision-making both within and beyond the hemodialysis unit. Each patient served as the centre of one of the six cases that included hemodialysis nurses, nephrologists, the dietician, the social worker, and the nurse practitioner regularly involved in the patients’ care. In two of the six cases, the patients’ unchanging health status throughout the study resulted in virtually no care-related decision-making data. However, the remaining four cases provided abundant, rich data at the heart of our analysis.

## Data collection and analysis

Over 12 months, we conducted bi-weekly observations and a total of 25 interviews with the patients about their in-hospital care experiences and decision-making processes.

Our 19 interviews with 11 health professionals provided multiple care perspectives for each case and helped us understand the larger hospital context and the care-delivery system. In addition, we observed care interactions during several specialist consults for one patient, during a long-term hospitalization of another patient, and during a comparatively short hospitalization of a third patient. Three of the cases also included data from family members or close friends of the patient. Two focus group discussions with the study's four collaborator health professionals (physician, nurse, social worker, dietician) clarified our preliminary findings and their clinical implications.

Data analysis occurred first concurrent with and again after data collection. Post data-collection analysis was first conducted thematically<sup>28</sup> within cases and then again across cases.<sup>29</sup> A third level of analysis, drew specifically on the interviews with health professionals and the field logs to provide a clear picture of the hemodialysis unit and the broader health care system of the hospital.

## Results

Overall, our study led us to understand (a) how patients with complex chronic illness engage in health-related decision-making, (b) how assumptions about patient decision-making are embedded in the structure and delivery of care, and (c) how those systemic assumptions can undermine patients' trust and compromise a collaborative approach to care that corresponds to patients' goals and values. In the site and case descriptions that follow, we present a detailed account of the observations that led to these understandings.

### *The site*

As in most health care systems in North America, disease and treatment

specialization shaped the layout of the hospital, the provision of care, and the organization of care-related information. Co-morbid conditions commonly associated with ESRD are treated by their associated specialists who are located in physically and administratively distinct parts of the hospital. For outpatient treatments and consults, our case patients received care in six different specialist services within the hospital (dialysis, ophthalmology, transplant, radiation, oncology, cardiology). During acute-illness episodes involving hospitalization, care was provided in five additional units (ER, ICU, surgery, plastics, medicine). In addition to the members of the multidisciplinary dialysis team (nurses, nephrologists, social worker, dietician, access surgeon, nurse practitioner), at least five more specialties provided care in three of the cases.

This complex distribution of care resulted in an equally complex distribution of care-related information essential for decision-making. For each patient, a medical chart held all care-related documentation and was housed in the hospital archives office which oversaw chart storage, retrieval, and movement for outpatient consults and in-hospital treatments. The disorder and unpredictable arrival of these charts was commonplace and recognized as a serious impediment to effective clinician-patient interactions.

The distributed nature of care and care-related information demanded that patients and health professionals use a number of means to share and/or replicate their information management in order to accommodate the care structure. One patient kept her own set of charts. Another patient insisted that one specialist write out recommended treatments for her to bring to another specialist. A third patient persisted in clarifying conflicting information from several different doctors about a medication he continued to be given well after the associated health concern had passed. Similarly,

health professionals compensated for weaknesses in the organization of care by using transient memory aids (e.g. notes written on scraps of paper and kept in a pocket; ongoing daily activity notes kept at nurses station); by keeping their own charts (e.g. dietician's blood results charts, separate from dialysis charts); and by engaging in unplanned (opportunistic) hallway chats about patient needs.

In Nephrology and Dialysis, a "double charting system" was used to compensate for this systemic weakness in accessing charts; most health professionals spoke of electronic health records (EHRs) as the obvious permanent solution. However, because health professionals select out and redistribute chart documents according to their specialty, EHRs would not necessarily address the need for a more holistic interpretation of the ill person.

While the importance of considering the whole person was not lost on the hemodialysis health professionals who work daily with people who have chronic co-morbid conditions, the care system offered no mechanism to systematically synthesize, interpret, and integrate the distributed care and information for the life of any one person.

### **Case 1: Lora**

Over 70 years old and with a history of recurrent breast cancer in addition to her years of living with kidney disease, Lora frequently said she was tired of being "poked and prodded" and wished "they could just give me a pill and leave me alone." Living alone and in the process of moving homes, Lora was reticent to begin investigating the nature of a kidney lesion that was discovered just prior to the study's start.

Having lived with and cared for both of her aging parents until their relatively recent deaths, Lora knew well the demands of caregiving and repeatedly expressed concern that she never become a burden to her

friends. Protecting these relationships and her autonomy was one of Lora's primary goals in deciding to move closer to the hospital and in refusing medical treatments that might require help during recovery at home. Lora also repeatedly mentioned that she took comfort in knowing that she could withdraw from dialysis, and thus end her life, whenever she felt the management of her illness was too much.

Shortly after Lora was told of her kidney lesion, she was given an appointment for a consultation with an oncologist. In our observation of this consultation, it was clear that Lora expected this appointment to be about her kidney lesion and was surprised when a radiation oncology resident spoke with her at length about the benefits of radiation treatment for prevention of Lora's recurrent breast cancer. When Lora quietly declined this treatment, the resident's supervisor joined the consult and repeated the information to make sure that Lora was well-informed in her decision not to accept their recommended treatment. Immediately following the radiation oncology consult, Lora had a second consult, this time with a specialist in kidney cancer who proposed two options: to do nothing, or to do a biopsy. But, in none of the consultations with the three specialists did Lora have a discussion of how the proposed treatments fit with her overall care values and goals.

Only after much discussion with her best friend did Lora agree to have the biopsy, which offered inconclusive results. Within this care system, Lora's decision-making was addressed as strictly medical and mostly binary: to receive radiation treatment, or not; to biopsy the lesion or not; to remove the kidney or not. In contrast, over the course of several months, Lora described the various life circumstances, personal values, and care goals that complicated her treatment-related decisions. First, the limited functioning of the kidney in question

allowed Lora to consume a bit more fluid than she could without it. Second, because of her age and history of cancer, Lora knew she could no longer hope for a kidney transplant to improve her quality of life. Finally, Lora was about to move homes, had a small support network and wanted nothing to do with treatments that would make her a “burden to others.”

### **Case 2: Alek**

Following a long history of kidney-related illness that began in his childhood, Alek received a kidney from his father. After 5 years, that kidney failed; and at the time of the study Alek, in his early-30 s, had been on hemodialysis for about four years. Late arrival for dialysis treatments, inattention to diet, and fluid overload had given Alek a reputation as a patient who was not yet “ready to change.”

Very early in the study, Alek suffered a life-threatening blood infection thought to have originated from unhygienic needling during dialysis. Alek explained that in response to the poor needling practices of certain nurses he had occasionally taken the needle from the nurse and needled himself. Some staff documented the suggestion that it was in such self-needling that bacteria was introduced. The infection threatened Alek’s heart and, for much of the study, he was hospitalized intermittently and seen by numerous specialists (ER, ICU, infectious disease, vascular, cardiology, pain clinic, transplant).

Unclear or contradictory information during and subsequent to hospitalization frustrated Alek and undermined his trust in the care being provided. For his first three consults with the cardiologist as an outpatient, Alek’s medical charts were not delivered to the physician who, therefore, asked Alek to provide a narrative of his complicated health situation. On another occasion, Alek eagerly awaited an

appointment with the Kidney Transplant Clinic only to discover that the appointment was with the Heart Transplant team. Alek was unaware of a possible heart transplant; and the health professionals involved in his care disagreed on whether he was a good candidate: a review of his charts suggested he was, but a conversation with his nephrologist suggested he was not.

When Alek had mostly recovered from his acute illness episode, he returned to dialysis as an outpatient less trusting of the health care system and, therefore, more determined to take responsibility for his illness management. He described his new approach to illness management as “a decision to take my own personal approach to treatments and medications” as opposed to “just going along with whatever the doctors said.” Alek began to manage his blood pressure medications on his own, without consulting health professionals. As a result of the distrust he developed of the care system during his hospitalization, Alek believed that he knew his own body better than anyone else could. Drawing on internet information, Alek adjusted his medication levels and decided which medications he no longer needed.

### **Case 3: Daniel**

A man in his mid-30 s who had been diabetic since age 12, Daniel lived with his parents in a First Nations community and had recently stopped working due to severe problems with his eyesight. His parents, a brother, girlfriend, and cousins were central to his social network. Daniel described himself as a heavy consumer of alcohol, cocaine, cigarettes, and marijuana prior to the study, but explained that he had quit most of these when his eyesight problems made him afraid of becoming blind. He described the threat of blindness as triggering a severe depression, and depression was a central theme in his illness narrative throughout the study.



Daniel believed that his depression, diabetes, and his kidney disease were caused primarily by stress that had been passed down through generations in his family. This stress and depression were not, however, the focus of the care Daniel received during most of the study.

Daniel was notorious amongst dialysis staff as not taking responsibility for his illness management and for relying on his mother to call in with excuses for his tardiness or absence. He was also viewed as poorly managing his diet, his fluid intake, and his medications. His primary nephrologist described, with palpable frustration, a conversation in which he it made clear to Daniel that to qualify for a transplant he had to “prove himself” by arriving for dialysis on time and by demonstrating a commitment to taking care of himself.

Early in the study, Daniel, in a fit of anger, kicked a wall and broke several toes in one foot. Over the course of about three weeks, Daniel’s toes were monitored by three of the unit nephrologists. When the infection worsened to the point of being gangrenous, Daniel was admitted to Emergency and then to the Medical ward where multiple nurses and doctors became involved in cleaning and assessing his foot. Consults were scheduled for Daniel to be seen in Vascular, Surgery, and Plastic Surgery. Two weeks later, several of his toes were amputated and amputation of his forefoot followed a week later.

Throughout his seven weeks in hospital, Daniel described himself as depressed, anxious, and insomniac. The constant presence of his parents, family and friends as well as the intervention of an indigenous healer (kept secret from hospital staff) did little to alleviate his struggles. After leaving the hospital, the depression persisted and Daniel spoke of stopping dialysis to end his life. He was given one appointment with a psychiatrist and then stopped all pain medications which he believed were the

cause of his depression. A gastrointestinal virus (caught while in hospital) and a clogged fistula complicated Daniel’s recovery, and a blood infection slowed the healing of his foot. By the study’s end, Daniel remained depressed and was angry about removal of parts of his foot that he believed had healed, about having seen the psychiatrist just once, and about how long it had taken for the health professionals to detect the blood infection that had delayed the healing of his foot.

#### *Case 4: Francine*

Recurrent skin cancer was one of the side-effects of the anti-rejection medications that Francine took for over two decades to protect her transplanted kidney. Having lived with kidney disease since she was a teen, this woman in her fifties was experienced in dealing with her disease and the health care system. A short time after her return to hemodialysis (when the transplanted kidney stopped working), the skin cancers increased and required regular monitoring, surgeries, and chemotherapy. While invasive and disruptive, management of these cancers had become part of Francine’s routine illness management and were weighed in the balance of her overall quality of life. She spoke matter-of-factly about her regular dermatology appointments and frequently invasive treatments. When removal of new cancerous tissue meant that Francine might not be able to enrol in her aqua-fitness class, she considered delaying treatment even though such a delay would likely mean a more invasive surgery followed by chemotherapy.

During one of Francine’s regular dermatology visits, the dermatologist asked her if she was on the waiting list for a transplant and told her about a new anti-rejection drug that could control the kind of recurrent cancers she was experiencing. This visit was the beginning of a decision-making thread

that continued through much of data collection. Francine began by gathering data from numerous medical specialists about the new anti-rejection drug. With close friends, our research assistant, and her nephrologist, she also discussed the pros and cons of a transplant. A successful transplant meant no more dialysis, dietary flexibility, and overall improved health. However, it would also likely mean the loss of disability and employment insurance payments because Francine would again be able to work. The stability that this modest income provided was very important to Francine who was very aware of the unpredictable nature of her illness, including the failure (sooner or later) of a transplanted kidney.

Despite her expertise with both the care system and her illness-management, Francine described herself as “procrastinating” in making the necessary appointments to determine her eligibility for the transplant list. One day, to her surprise and relief, Francine learned that the transplant clinic had requested her records in order to begin that very assessment process. Who had made the decision to initiate the assessment process and when was difficult to know and seemed of little or no concern to Francine. She was simply relieved that the uncertainty was over and the decision had been taken.

## Discussion

These four cases and the health care setting in which they occurred led us to a better understanding of how patients with chronic co-morbidities engage in decision-making; and how the health care system makes assumptions about, and thereby impacts, patients’ decision-making.

### *Patients’ decision-making*

*Embedded in uncertainty.* Co-morbid ESRD patients’ decision-making is often about

striking a balance between a present known quality of life and an uncertain one in the future. Decision-making for this population is often about running the risk that decisions involving sacrifices to current quality-of-life will not pay off in one’s future quality-of-life.

One of the few benefits of being on dialysis for some patients is the financial stability of disability insurance. For dialysis patients, such as Francine, who are young and healthy enough to work, a successful transplant can mean a loss of disability insurance and the financial stability it provides. In the context of chronic co-morbid illness, unpredictability is a given. Transplants can fail; medications can cause debilitating side-effects; infections are a constant threat. Stability, therefore, is precious. Thus, Francine weighs the potential benefits of a kidney transplant against the financial and medical uncertainties it introduces. For Lora, withstanding the unpleasant side-effects of radiation treatment for breast cancer makes no sense given the unpredictability of her other co-morbid conditions and her sense of a declining quality of life. In all of the cases, patients’ shifting health status demanded some shifting of their sense of themselves in the future, and their care goals and values in the present.

*Fluid and cumulative.* In contrast to the medically-siloed treatment of patient decision-making by the care system, we observed patients’ decision-making to be fluid (ruminated on, revisited, avoided); and cumulative (referencing past experiences; the result of several prior decisions). The fluid quality of decision-making was most evident when decisions leading to a particular action (e.g. amputation) set off another series of care-related decision-making activities: decisions about rehabilitation, pain medications, appointments, future surgery, in whom to confide, from whom to seek information.



Similarly, decisions were cumulative or inter-related; they were rarely about one issue. Removal of cancerous tissue might also mean not participating in an exercise regimen. Undergoing surgery might also mean delaying a long-anticipated move of homes. Receiving a transplant might also mean loss of financial stability. Finally, decision-making was often distributed as a complex activity shaped by different kinds of information that are located in many people of whom the patient is but one.

*Relational.* Perhaps to mitigate some of their life's uncertainty, patients sought decision-making support from a constellation of significant relationships, suggesting that decision-making is more a relationship-centered activity than an individual one. Both Lora and Francine repeatedly consulted close friends and both took seriously the medical advice of the health professionals involved in their care. Daniel's mother collaborated in his decisions to arrive late or skip dialysis. Patient-clinician relationships also affected patients' decision-making because those relationships shaped patients' confidence in the quality of the care provided, in the legitimacy of the medical advice given, and in the value of acting on that advice. Alek's desire to repair his reputation with dialysis staff underscores his belief that those relationships shape the quality of his care. Keeping secret the visit of a traditional healer to see Daniel in hospital is an almost iconic example of suspicion undermining collaborative decision-making regarding alternative approaches to healing.

*Integrative.* For the study's patient-participants, episodic and day-to-day health-related decision-making blended together in the larger ongoing project of integrating illness into one's current and anticipated or hoped-for life. As people became more familiar with the ups and downs of their

illness, what was once a monumental medical experience could become part of the ongoing routine of living with chronic co-morbidity. Recurrent skin cancer and its treatments became part of Francine's day-to-day balancing of present and future quality of life. Lora responded to a potentially cancerous kidney lesion not as a health crisis but as something to be dealt with in due time, that is, after she had completed her anticipated move to a new home. Repeatedly, we observed that patients worked hard to blend medical and nonmedical decision-making into their life with illness as a whole.

### *Systemic assumptions about and impact on patient decision-making*

As in the practice-based literature, patients' health-related decision-making in the hospital care setting seems to be viewed as isolable, medical, binary choices that are generally negotiated in patient-physician dyads. Like the care system itself, patients' decision-making opportunities were organized into disease-specific silos. For example, Lora met separately with the breast cancer radiation specialist and her resident, the kidney cancer specialist, and the nephrologist who addressed separate elements of what were for her an inter-related cluster of health-related concerns. Similarly, Alek met separately with the kidney transplant and heart transplant specialists to consider next steps in response to an acute illness episode that threatened his life. Given the expertise that Francine had developed to compensate for the care system's communication weaknesses (and the high praise she received for this behavior), it seems clear that patients receive little support in making sense of or decisions about the complex interplay of their co-morbidities. It is in this context that patients are expected to make appropriate health-related decisions.

We also gained insight into how the structure and delivery of care can shape patients care goals and the integration of their illness and life according to those goals. We observed the valuable expertise of myriad medical specialists sometimes culminate in fragmented care instead of a cohesive care plan. Disarray in medical charts inhibited a holistic understanding of a patient's health, and acted more as storage units for specialist information than as the narrative representation of patients' illness/wellness trajectory. Bedside teaching rounds by more than one team of medical specialists left patients confused by differing, sometimes contradictory, medical recommendations; this confusion, in turn, undermined patients' confidence and trust in their care providers and the system in general.

The distribution of care according to disease specialty works well for short-term, acute-care needs; but when faced with long-term, multi-morbid chronic illness this carefully distributed care becomes fragmented and inefficient.<sup>30,31</sup> Charts do not arrive for consultations; patients overhear conflicting information about treatment options; treatment consultations can fail to include discussion of patients' overall care goals or life circumstances; radical medical interventions (e.g. amputation) can involve several specialists from several units yet fail to address the psychological needs of the person undergoing the intervention. While these problems concern all patients, not just those with chronic illness, they are recurrent features in the care of chronically, co-morbidly ill patients whose holistic, long-term needs are poorly addressed in a health care system designed for an acute-care focus.

## Conclusion

At the interface of health care delivery and people with co-morbid ESRD, we see how acute-care health care institutions are organized around what they do best: identifying

and solving discrete, short-term health disorders. Expertise in responding to long-term interventions for illnesses that are permanently embedded in a person's life is underdeveloped in this context. Recent literature discusses this shift from acute to chronic care needs;<sup>32</sup> our data provide additional insights into the decision-making challenges associated with this shift.

We found specialists' care focused on discrete elements of the patients' co-morbid condition, while patients' decision-making focused on their experience of illness as a dynamic whole. Furthermore because of the oft-changing nature of their illness, the patients' decision-making was an ongoing process of weaving their illness and their life into an integrated whole. The fragmented care system seemed remarkably ill-designed to notice, much less facilitate, these patients' pursuit of wholeness.

Ideally, decision-making in the context of chronic illness would occur as part of a longitudinal conversation between health professionals and patients that recognizes and responds to changes in patients' illness / health, their life circumstances, and their care values and goals. This requires health professionals to masterfully draw on both interpersonal and medical expertise in order to first understand the implications of patients' shifting care values and goals and to then collaborate across disciplines and professional roles in ways that help patients achieve those goals.

The need for a return to more holistic care is argued in several literatures including patient-centered care, relationship-centered care<sup>33</sup> and whole person care.<sup>34-36</sup> Cassell<sup>36</sup> proposes that medicine needs to radically reorient the priorities of care to focus on the purposes, goals, and well-being of the individual patient. Integral to such a reorientation is at least one member of a care team knowing the patient as a whole person and consistently advocating for that patient in the myriad complexities inevitable in the

care of people with multi-morbid, chronic illness. This patient advocacy would be part of the process of healthcare institutions themselves becoming whole and developing an integrated response not to disease, but to the inter-related needs of people with illness.

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