



## 'Non-compliance' as illness management: Hemodialysis patients' descriptions of adversarial patient–clinician interactions

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### ABSTRACT

With only 50% of patients in developed countries following the therapies prescribed for them by health professionals, “non-compliance” is commonly described as causing increases in morbidity, hospital visits, and overall healthcare costs. A plethora of non-compliance studies have failed to identify consistent predictors for, or solutions to, patients' non-compliance. Our longitudinal (September 2006–September 2008) participatory action research (PAR) focused on (a) understanding hemodialysis patients' perspectives on the challenges and solutions to living well with their chronic illness and (b) taking action to improve this population's quality of life. The study's participants included seven purposefully sampled patients in two hospital hemodialysis units in Canada. A small sample size was essential to accommodate our commitment to conducting a PAR study with this patient population whose unpredictable health status presented significant challenges to recruitment, follow-up interviews, and participation in data analysis. Data collection and analysis over 2 years included over 100 h of ethnographic field observation, bi-weekly unrecorded and 12 audio-recorded in-dialysis interviews, five video-recorded life-history interviews, two video-recorded focus groups, and five video-recorded dialysis treatment sessions. Thematic content analysis drew attention to patients' descriptions of adversarial interactions with health professionals. In these interactions, three points of tension were identified: (a) between whole person care and “assembly line” treatment, (b) between patient knowledge and medical expertise, and (c) between shared decision-making and “digging to find out”. The article concludes that these adversarial relationships are indicative of a lack of trust stemming from health professionals' failure to interact with patients as whole persons with unique expertise on their bodies, their experience of illness, and their lives.

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### Introduction

Given the relatively recent shift in medical care, away from primarily acute illness and toward chronic illness, and given the difficulty of treating and managing complex, co-morbid chronic illnesses such as end-stage renal disease (ESRD), it is not surprising that abundant clinical research across medical disciplines has been unable to identify predictors of and solutions to patient non-compliance (Christensen, 2004; Segal, 2005, pp. 133–152; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Clinical research on the compliance of hemodialysis patients is no exception. Findings are commonly viewed as problematic due to inconsistency in measurement parameters and definitions of non-compliance. These inconsistencies contribute to a huge range in its reported prevalence

(e.g. Kaveh & Kimmel, 2001) as well as conflicting data on the relationship between compliance and mortality (e.g. Leggat, 2005) and between compliance and quality of life (Quinnan, 2007).

In an effort to better recognize the substantial role of patients in healthcare, the term “adherence” (defined as “the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider” (WHO, 2003, p. 17)) introduced more awareness of chronically-ill patients' rights and responsibilities in their illness management. However, the conceptual shift between compliance and adherence is so subtle as to go virtually unnoticed in research and practice where “compliance” and “adherence” are used interchangeably. In this article, we use “compliance” to refer to both terms.

The literature on hemodialysis patients' non-compliance identifies a range of reasons for this behavior. Inadequate education about their illness and illness management (e.g. Constantini, 2006; Krespi, Bone, Ahmad, Worthington, & Salmon, 2004) and the desire for more control over an unpredictable chronic illness (e.g. Leggat,

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2005; Quinnan, 2007) are commonly cited explanations for dialysis patients' non-compliance. Lack of family support and the complexity of treatment regimes are other commonly cited reasons (e.g. Loghman-Adham, 2003). We further explore patients' reasons for non-compliance both in our discussion of the concept of "concordance" and in the section describing our findings.

Because of sustained criticism of the paternalistic overtones of compliance models of medicine and because of decades of compliance research that has failed to effect change in patient behavior or healthcare costs, the UK's Royal Pharmaceutical Society and Department of Health introduced the concept of "concordance" defined as "agreement between the patient and healthcare professional, reached after negotiation that respects the beliefs and wishes of the patient in determining whether, when and how their medicine is taken, and (in which) the primacy of the patient's decision (is recognized)" (Marinker et al., 1997, cited in Cushing & Metcalfe, 2007, p. 1049). The definition acknowledges the significant role that chronically-ill patients play in the daily management of their illness and identifies health professionals as expert medical resources who can facilitate patients' successful self-management.

Central to concordance is a mutually-respectful patient–clinician relationship focused on negotiated agreement (Cushing & Metcalfe, 2007) with an understanding of chronic illness management as embedded in the complexities of patients' life worlds (Burke, 2007; Gately, Rogers, & Sanders, 2007). Such patient–clinician relationships are increasingly viewed as core to patients' successful self-management (Constantini, 2006; Ricka, Vanrenterghem, & Evers, 2002) and to shared decision-making which integrate medical expertise and patients' experiences (Barratt, 2008; Department of Health, 2001, p. 38; Karnieli-Miller & Eisikovits, 2009; Lorig & Holman, 2003).

However, in light of patients' reasonable concerns about, for example, the risk of adverse drug reactions, addiction, and stigma (Pound et al., 2005), or the material and social barriers (e.g. poverty, gendered roles) to compliance (Bissell, May, & Noyce, 2004), concordant patient–clinician relationships cannot be seen as the panacea to non-compliance. But, Bissell et al. (2004) argue that while such relationships may not directly affect health outcomes, they seem to increase health professionals' understanding of the subjective aspects of living with a chronic illness. Such understanding may facilitate the integration of what many argue is useful experiential knowledge from patients (e.g. Caron-Flinterman, Broerse, & Bunders, 2005; Stockl, 2007).

In our two-year, participatory action research (PAR) study, patient-participants and dialysis health professionals offered differing perspectives on how patients should go about living well with their chronic illness. Significantly, patient compliance figured prominently as a point of tension in patient–clinician relationships. This article focuses on that tension in the context of hemodialysis and how that tension played out in the patients' management of their illness. More specifically we report findings regarding two specific research questions: (a) how do hemodialysis patients describe health professionals' involvement in their care? (b) how can these descriptions be understood in the context of these patients' illness management?

## Methods

### Methodology

Film-based PAR framed the design and execution of our 2-year study (September 2006–September 2008) in Canada. Funded by the Kidney Foundation of Canada and approved by our university's research ethics board, our study focused on (a) understanding hemodialysis patients' perspectives on the challenges and solutions

to living well with their chronic illness and (b) taking action to improve this population's quality of life. With its commitment to improving the lives of vulnerable people partly through bi-directional researcher–participant education, PAR is a challenging but appropriate research methodology for a wide range of qualitative health research (Allen & Hutchinson, 2009; Iedema, Long, Forsyth, & Lee, 2006; Khanlou & Peter, 2005; Stringer, 1996; White, Suchowierska, & Campbell, 2004). The hemodialysis population is especially vulnerable to unpredictable, life-threatening diseases in addition to kidney failure, and it is highly dependent on the health professionals who deliver patients' thrice-weekly, life-sustaining treatment. A PAR approach to our study provided the patient-participants with the opportunity to both explore their own and their peers' experiences and to use those experiences to teach others. As study collaborators, the patient-participants saw themselves as educators who, through film, could teach fellow patients, health professionals, and the general population about the realities of living with their disease. With additional support from several donor organizations, both local and national, a bilingual version of the DVD (Allen, Hutchinson, & Wainwright, 2008) has been distributed to over 280 Canadian healthcare affiliated institutions and organizations and has been used in nursing, social work and medical education sessions in both the UK and Canada.

### Recruitment and sample

We used a combination of purposive, convenience, and snowball sampling to recruit our patient-participants. With the help of health professionals in two hospital-based hemodialysis units in Canada, purposive sampling was used to identify English-speaking patient-participants who were interested in and capable of (a) discussing their experiences of living with chronic kidney failure; (b) engaging in such research discussions over the course of the study; and (c) collaborating with the other participants and researchers in adjusting design and providing feedback on the ongoing data analysis. We purposefully sought a balance of male and female participants who together represented a range of age, cultural origin, and experience with dialysis and chronic kidney disease. Our sampling was also one of convenience because we were drawing on the populations from two dialysis units where one of the researchers (TH) had long practiced nephrology and where gaining access to patients and health professionals was thereby greatly facilitated or convenient. Finally, we also used snowball sampling when earlier patient recruits, who tended to be more experienced with dialysis, identified other patients who they felt met our purposive selection criteria (interest, ability, range of age/culture/experience). Of the 20 patients approached by the lead researcher during patients' dialysis treatment, seven agreed to participate. A small sample size was essential to accommodate our commitment to conducting a PAR study with this patient population whose unpredictable health status presented significant challenges to recruitment, follow-up interviews, and participation in data analysis. The patient-participants (3 women, 4 men) were diverse in terms of age (38–63 years), range of experiences with renal replacement therapies, and countries of origin (Trinidad, Malaysia, Canada). Four of the seven patients received disability and welfare support, one received a retirement pension, and two were self-employed.

### Data collection and analysis

Data collection and concurrent analysis occurred over 18 months. Four months of intensive field observation occurred concurrent with recruitment. Handwritten notes were taken during weekly dialysis rounds with health professionals in each site

and before and after recruitment interviews with patients on the dialysis units. Upon completion of patient-participant recruitment, collection of observational data in dialysis rounds was reduced to bi-weekly and then monthly attendance. In the dialysis units, observational data collection continued throughout the study. Field notes were taken in various locations on the units (e.g. patient chairs, nursing station, waiting area) and included abundant informal conversations with health professionals about disease treatment and patient care.

The first six months of patient-participant interview data included bi-weekly, unrecorded, in-dialysis interviews; 12 audio-recorded in-dialysis interviews; one video-recorded focus group; and five video-recorded life-history interviews in patients' homes. After our first focus-group session with the patient-participants (month 6), we moved from audio-recorded to primarily video-recorded data and hired a documentary film-maker to ensure high quality recording and ease with editing. Video-recorded data (burned on to DVDs for each participant's viewing and feedback) facilitated the involvement of patient-participants whose vision and dexterity were too compromised to work with written transcripts. Furthermore, the patients saw video as ideal for potentially raising awareness about the realities of chronic kidney failure, a goal for the study that was identified after the first focus-group session.

In collaboration with the researchers and the documentary film-maker, the patients were able to participate in data analysis through the 'proxy-editing' (member-checking) of various versions of edited video data (months 11–13). Due to the physical constraints of the video-editing room (confined space in a home with stairs), only the lead researcher (DA) and the film-maker actually edited the video material. The video data from all focus-group discussions and individual interviews were separated into meaningful units which were then named, thematically organized, and eventually shaped into a much more concise version of the longer original raw data (group discussion or interview) by cutting out false-starts and redundancies and by highlighting those data chunks that were most significant in relationship to the study's questions and purpose. These more concise versions of the data were then copied on to DVDs and shared with participants. Aside from one patient's request that more appreciation for health professionals be captured (which was accomplished in future filming), the participants requested no changes through this "editing-by-proxy" process and stated that the more concise versions of interviews and focus-group discussions accurately reflected the tone and content of those discussions and interviews.

Eventually, the patients' enthusiasm for the power of video as a means of communicating their experience of chronic illness led to the decision to create a documentary film about their experience of living with kidney failure. To this end, during the last five months of data collection (months 14–18), we video-recorded a second patient focus group; obtained hospital and university research ethics consent to video record patient-participants during their dialysis treatment; and then recorded five patient-participants during treatment. In the final six months of this two-year study, the lead researcher collaborated with the documentary film-maker to reduce 25 h of video data into a 46-min educational documentary. Various versions of this final film were subjected to an additional round of patients' 'editing-by-proxy' as described above.

The findings for this paper are derived largely from the various levels of analysis that occurred during the film editing experience. That analysis, conducted by the lead researcher in collaboration with the film-maker, included both the more traditional coding and organization of the data into themes, as well as attention to the esthetic dimensions of the data that is so central to the making of a visually pleasing, emotionally moving, and psychologically compelling film. For purposes of this and other academic publications

of the study's findings, in addition to the data analysis that occurred as a result of the film editing process, we also transcribed all audio- and video-recorded interviews as well as focus-group sessions and submitted them to an additional round of iterative, thematic, content analysis (e.g. Hsieh & Shannon, 2005). Field notes provided rich data for understanding health professionals' perspectives on patient care and for clarifying or contextualizing interpretations throughout data analysis. Interview excerpts included in the findings section are tagged with pseudonyms.

## Findings

Striking in our analysis of patients' descriptions of their illness management were their relatively frequent descriptions of adversarial and sometimes confrontational interactions with health professionals. These descriptions were particularly significant in light of the 'non-compliance' discourse (documented in over 200 pages of field notes) frequently used by health professionals in their discussions of, for example, patients' transplant eligibility, health complications, and acute illness episodes. From our analysis of the patients' descriptors of adversarial interactions with health professionals, three points of tension emerged: (a) between whole person care and "assembly line" treatment, (b) between patient knowledge and medical expertise, and (c) between shared decision-making and "digging to find out".

- (a) Between whole person care and "assembly line" treatment: "that connection, it's not there"

When I first started dialysis, the atmosphere in the unit ... was one of camaraderie with the nurses and the other patients. ... We felt like a family and were very close. We took care of each other. It was an entirely different feeling than goes on now. ... We don't speak to our nurses any more. The nurses are now technicians. Our doctors are um ... are not warm. ... If I have a problem, they're not going to come over and try, "Oh yeah, it hurts you there? Let me feel that." They don't do that any more. Now they're "stand-offish". They stand at the bottom of the bed, look at you, "How you feeling today?" "Fine". "You have a problem?" "Ya". "Okay, well this is what we'll do". And then they go, or they sign the little paper and walk away, and that's it. The whole system has gone from one of compassion and caring and loving to one of adversarial, where it's us against them (Scott).

Having begun dialysis many years ago, Scott witnessed the gradual erosion of various healthcare services and healthcare relationships associated with his care. This erosion is the unsurprising consequence of greater numbers of dialysis treatment recipients with either the same or fewer resources. As a result, Scott has long made it his business to "fight" for the various services he sees as central to the care of people with ESRD. His fight increasingly occurs in what Gail, a more recent patient, described as "an assembly line" dialysis environment.

In terms of the surroundings, I find it's as if we're on an assembly line, because when you come in, you have to wait. You're being called, and there is no interaction with staff and patients. For what I knew, you have to have some interaction, but they always had something to do. They're always in a hurry. There is not that communication.

In the context of their thrice-weekly, machine-driven treatment, most of the patients described the dialysis nurses as engaged in a "regimented", hurried practice focused more on regulating the dialysis machines than on what Gail referred to as "bedside nursing" and "tender loving care": "If the [dialysis machine] alarm

goes off, she'll [the nurse] come to see what it says. ... But they're not coming to check on you per se".

Regimented interactions with health professionals were described as occurring across the many medical disciplines with which dialysis patients frequently interface (e.g. vascular, orthopedics, ophthalmology, and emergency) due to these patients' high levels of co-morbidity. Patients attributed the lack of interpersonal connection with health professionals in part to the efficiency focus of the medical system, as well as to health professionals' dismissive attitudes toward patients' experience-based knowledge. Patricia describes her interactions with such physicians as lacking "connection".

It's like this. They have the authority, and they know they have the authority. But they don't take the conscious time to be um ... I'm not saying catering ... but just that connection. It's not there (Patricia).

Without "that connection", Patricia felt that she was left to live with the decisions of physicians who had not listened to or considered the consequences for her "whole situation".

You're [doctor] not listening to the whole situation. You took a piece of it, made your analysis, made your decision, and you've moved on. But I'm still here living with whatever you left me with (Patricia).

The patients' desire for wholeness, for consideration of the "whole situation" and the whole person, is quite literally represented in Kelly's struggle to protect her leg from amputation.

It was just out of the fear of losing my leg, not losing my life that I said no, that I refused the amputation. And I still have my leg today [...] I was in the hospital for a year where I had nurses on occasion saying to me 'we have people like you that try to hang on to their limb, but they end up losing it anyway'. And I really did feel at a point [...] that I was wasting their time (Kelly).

Kelly's refusal of the medically prescribed amputation might be understood as a form of "non-compliance"; however, with her leg in relatively good health two years later, Kelly interpreted her refusal as a wise decision which protected her against what patients describe as "trial and error" medical practices. "They try different things and if it works it works and if it doesn't, well, you know, that could lead to other problems" (Larry). When it didn't work, the patients experienced a kind of compliance-gone-wrong and they called into question the authority they had granted to the health professionals providing their care. Patients described themselves as gradually learning that "no two patients are alike", that regimented, by-the-book practices were suspect, and that patients must develop and trust their experiential knowledge of illness as much if not more than the expert medical knowledge of health professionals.

(b) Between patient knowledge and medical expertise: "Compliant to a point"

The first couple of years, let me tell you, I was compliant as can be [...] and it just came to a point that, I think after my lupus and all the ups and downs, ... I would do everything. Then I'd be sick or I'd be hospitalized for a week or something. So by the time [...] I came to dialysis, I was compliant to a point. I was like, I'd be doing the average of stuff, you know, like just tell me what I can do, what I can't do, and then I'll, I'll paint my own little picture from there (Patricia).

Treatment-knowledge, body-knowledge (knowledge of their body's unique responses to medical interventions), and self-advocacy dominated the patients' discussions of how to talk back to generic, by-the-book treatments, and how to individualize their

illness management to meet the unique and changing needs of their bodies and their lives. Like Patricia, most patients described their treatment- and body-knowledge as developing through observation and experience over time.

Patients paid close attention to the various clinical measures used to assess their health behaviors and health outcomes: time on dialysis, inter-dialytic weight gain, blood pressure, rate of blood flow during dialysis, potassium and calcium levels in their blood tests. Patients saw these clinical measures as valuable; and to the extent that it was possible, they integrated these resources into their illness management. Scott recalls that when he began dialysis in the 1970s, frequent blood tests were an empowering learning tool for patients. "That's how I learned what I could eat and not eat. [...] Now we only do our bloods once a month. I've always contended that was a mistake" (Scott).

Larry describes his experiential learning about the relationships among pump speed, needle adjustment, potassium levels and nursing practices:

[Rather than taking time to adjust the needle, some nurses] will just simply lower the blood flow. With the lowering of the blood flow, you get less cleaning and because of that, I've had three occasions where I was scratching like crazy from the phosphorous that wasn't extracted from the body. So then I learned to say "no, no, keep it up" (Larry).

Sam describes learning from his peers about how to protect himself against dialysis-induced radical drops in blood pressure.

So as you go in [to dialysis], the nurses are in charge. They'll tell you what is your dry weight. You'll accept what they say, and then you have problems because the dry weight is not the correct weight. They took too much water ... and you have low blood pressure and you start having heart problems and all kind of things start happening. And then as you go, you need other patients to tell you, "Hey, don't tell the real weight to them. Keep some for yourself" (Sam).

When lying about his dry weight was inadequate to adjust for the excess fluid acquired over a weekend without dialysis, on at least one occasion Sam attempted to get the treatment he felt he needed by defiantly insisting that he be dialyzed for 4 h rather than the prescribed three and a half. When one nurse refused, Sam described first rejecting her care ("I tell her, 'I don't want you [...] Please go. Find somebody else'") and then appealing to the authority of the doctor to "write it on the chart so that [the nurses] won't question me" (Sam).

From the perspective of an experienced and knowledgeable patient, Sam's defiance might be interpreted as admirable self-advocacy. However, from the perspective of the clinicians responsible for his care, Sam's behavior might be viewed as non-compliance that is both obstructive (prohibiting nurses from doing their job) and/or risky both for himself (if his treatment demands are unhealthy) and for the clinicians held responsible for his care. Such potential risks highlight the importance of patient-clinician collaboration in decisions about illness management.

(c) Between shared decision-making and "digging to find out": "Let's see how we can work this together"

Okay, my choices are more limited right now, but there's still choices to make. I want to make them, and that includes all my illness, in a hospital atmosphere or anything. ... Even my interactions with doctors; it's like I want to have the influence. I want to have choice about what's happening to me. So I don't really want to have that doctor that says, "okay, I'm the doctor. You're the patient, and this is what we're going to do". I'm like

“you’re the doctor. I’m the patient, and let’s see how we can work this together”. I want to be an influence on that decision. I want to help make the decisions because I think I have a lot of [to] input on my situation (Kelly).

In describing her desire for patient–clinician dialog, Kelly captures well the significance of moving away from authoritative delivery of medical expertise toward collaborative relationships with health professionals. Such relationships allow her “to have an influence” on decisions regarding her illness management. Kelly’s desire “to help make the decisions” and “to see how we can work this together” highlights both her need to be heard and her need to know and understand. She wants health professionals to both respect her experience-based knowledge and to enrich that knowledge by sharing their medical expertise with her.

A long-time dialysis patient, Scott believed strongly in the power of knowledge for patient autonomy. He felt that patients should know the details of their disease, its treatment, the medical system in which treatment occurs, and the unique ways in which their body responds to treatment. However, while all of the patients described such knowledge as essential to their sense of control, autonomy, and well-being, they also described such knowledge as difficult to access. They used metaphors such as “digging for”, “fighting for”, and “going after” information when they spoke of learning about disease treatment and illness management. “You have to inquire, you have to inform yourself, you talk to other patients, you have to dig to find out more than what they’re telling you” (Larry).

That patient-peers were considered a common and valuable information source was complicated by the reality that “everyone’s situation is not always similar to yours”. Patients wanted information that would allow them to find their own “middle ground”, to let them know “what’s out there for you [and...] leave it up to you if you want to take it or if you don’t want to take it”, and to help them anticipate their illness trajectory. Instead of easy access to clinical information, patients felt that certain information was hidden. Larry felt that “they try to keep the negatives away from you [...] because it might not happen to you. Different things happen to different people”.

A sense of secrecy about the “negatives” was reinforced by the virtual silence in the unit about patient deaths. In a focus-group conversation about death and dying, the patients described “get [ting] used to seeing people just disappear” and feeling that the health professionals in the unit “keep it hushed”. Moreover, in that same focus-group discussion, the patients agreed that when health professionals did occasionally speak of death on the unit, “they usually say the patient is a non-conforming patient, that he’s not doing the right thing. It’s usually the patient that gets blamed for dying”.

## Discussion

Conducted in publicly-funded, accredited, university-based teaching hospitals, within a Canadian socialized healthcare system, our study draws attention to the challenges of establishing and maintaining trusting and concordant patient–clinician relationships even in a medical institution that promotes the highest standards of care. Given the small number of participants in this study, the patient perspectives presented in this article cannot be interpreted as representing the experiences of all dialysis patients. However, neither should these perspectives be interpreted as merely coming from a biased group of unhappy patients. Indeed the patients’ perspectives on life with their disease were viewed by health professionals in the study (as well as those who have subsequently watched the video) as not surprising and fairly common. We did not make an in-depth study of health professionals’ own perspectives on these

patient–clinician relationships and offer, in this report, patients perspectives. Further research would discover different but equally valuable perspectives from health professionals.

Our findings support both the need for and the value of concordant patient–clinician relationships. However, the data also problematise concordance by drawing particular attention to adversarial patient–clinician interactions that are associated with technology-driven, efficiency-focused care which excludes patient knowledge. Ironically, the mistrust that such care introduces into the patient–clinician relationship diminishes the collaborative effort needed for optimal care in the context of chronic illness. Patients who are unable to trust their clinicians are, of course, less inclined to openly communicate with those clinicians or integrate their medical expertise.

The patients’ esteem for and trust in their health professionals was directly tied to the health professionals’ ability to listen to and integrate the patient’s explanations of their illness management as legitimate and informative. Failure to engage with the patients’ experiential knowledge (Caron-Flinterman et al., 2005; Stockl, 2007) and with patients themselves as unique rather than generic seemed to undermine health professionals’ authority and the patients’ trust. To protect themselves against what Segal (2005, pp. 133–152) and Pound et al. (2005) describe as the not-uncommon dangers of compliance-gone-wrong and against dismissive, judgmental, or misinformed health professionals, patients described themselves as having to fight against rather than collaborate with health professionals and the healthcare system. The various “non-compliant” behaviors in which the patients engaged – lying to and or shutting down communication with health professionals, refusing recommended treatments, adjusting diet and medications, refusing care from particular health professionals – were all described as necessary, self-protective strategies against the medical practices of untrustworthy health professionals. The erosion of trust that led to this unpleasant and perhaps dangerous impasse was frequently experienced by the participants as bi-directional; that is, patient-participants neither trusted nor felt trusted by the health professionals as legitimate knowers.

Our data suggest that a possible explanation for this erosion of trust is the absence of what Bissell et al. (2004) describe as “interactions with health professionals that foster shared *understandings*” (p. 858). Insufficient attention to patient–clinician relationships that “foster shared understanding” diminishes the possibility of dialog between clinicians and patients that might increase the “health literacy” of both. Neglect of the patient–clinician relationship in the context of chronic illness may contribute to a loss of perhaps clinically valuable information about individual patients’ unique responses to and management of generic medical interventions because patients may withhold information which often, as Pound et al.’s (2005) literature review suggests, elicits health professionals’ criticism or dismissal. However, our data highlight another, perhaps more important, consequence of neglecting this relationship: Clinicians’ failure to recognize and support patient knowledge likely contributes to the development of adversarial patient–clinician relationships. In no other context is patient collaboration more important than in the ongoing management of chronic illness and disease where patients’ daily self-care can be in harmony or in conflict with health professionals’ medical interventions. By devaluing chronically-ill patients’ experiential knowledge, does medical practice inadvertently contribute to what it so commonly refers to as “non-compliance”? As patients’ illness expertise has been sidestepped in favor of technologically-discernable disease information, might patients’ once-valued observational skills atrophy? Might validation of and collaboration with patients improve the quality and value of their observational skills as well as their adherence to medical regimens?

According to our data, the management of chronic illness is best achieved through an approach which acknowledges the distinct and complementary knowledge of patients and health professionals (Reading, 1977). Like Segal (2005, pp. 133–152), we believe that there needs to be a balance between patient and clinician expertise. Dialysis health professionals generally know more about medications, adequacy of dialysis, and control of blood pressure, for example, than do their patients. But health professionals' medical expertise needs to be combined on a case-by-case basis with the patient's knowledge about their own body and life in a way that leads to genuine cooperation and concordant care of the whole person. We are not advocating a reversal of the knowledge hierarchy; as in the work of Bissell et al. (2004) our data do not suggest that this is what patients want. What the data do suggest, however, is that these patients want to be treated as whole persons and respected as knowledgeable partners in the management of a complex illness which occurs and is experienced in not just a body, but in a unique life-world.

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