



## '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

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