

You Cannot Choose Your Family: Sociological Ambivalence in the Hemodialysis Unit

Patricia M. Wilson¹, Jonathan D. Reston², Rebecca Bieraugel³, Maria Da Silva Gane³, David Wellsted², Maxine Offredy², Ken Farrington³

¹ University of Kent, United Kingdom

² University of Hertfordshire, United Kingdom.

³ East & North Hertfordshire NHS Trust, United Kingdom

Corresponding Author:

Patricia M. Wilson, Professor of Primary and Community Care, Centre for Health Service Studies, University of Kent, George Allen Wing, Canterbury, CT2 7NF

E-mail: p.m.wilson@kent.ac.uk

Abstract

Living with end-stage renal disease is challenging and requires a great deal of self-management, but little is known about the experiences of patients and staff around the subject. We held six focus groups in three hemodialysis units, each unit hosting 1 staff and 1 patient focus group. A total of 15 staff members and 15 patients participated. We employed thematic analysis using a priori and emerging codes. Five key themes emerged: challenges, enablers, complex balancing acts, good patient/bad patient, and the hemodialysis unit as a family. We explored the family metaphor further through the work of Bourdieu, but concluded that relationships in the hemodialysis unit most closely fit the concept of sociological ambivalence. We present an explanatory framework around inherent tensions characterizing relationships within the hemodialysis unit and highlight implications for facilitating self-management and developing collaborative approaches to care.

Keywords

focus groups; health care, culture of; nephrology; participatory action research (PAR); relationships, health care; self-care; sociology;

Self-management is increasingly seen as an important component of the individual's experience of chronic disease, such as asthma, diabetes, and cardiovascular disease (Bodenheimer, Lorig, Holman, & Grumbach, 2002). This holds true for the academic literature, clinical practice, and national and international policy making (Department of Health, 2005; Nolte & McKee, 2008). In comparison to other chronic conditions, end stage renal disease (ESRD) has received relatively little attention from a self-management perspective (Novak, Costantini, Schneider, & Beanlands, 2013). This is especially true of center-based hemodialysis, which we focus on in this article.

ESRD occurs when the kidneys have no (or very little) remaining functionality. This condition can either follow years of gradual decline or occur in response to sudden injury or infection. It can be present from birth or occur at any age, but becomes more common as age increases and is associated with a number of comorbidities, such as diabetes and cardiovascular disease. ESRD causes the buildup of toxins in the bloodstream, fluid overload, high blood pressure, cardiovascular disease, bone and mineral-related problems, such as vascular calcification, and death. This condition can be controlled (but never fully cured) by either a kidney transplant or renal replacement therapies (RRT), such as hemodialysis or peritoneal dialysis. These can replace some, but not all, of the lost renal functions. ESRD is a comparatively rare condition, with 842 patients on RRT per 1,000,000 people living in the United Kingdom, a total of more than 53,000 (Renal Association, 2012). The comparable figure in the United States is more than 594,000 (Collins et al., 2013).

ESRD entails a huge treatment burden for the individual. Some RRTs can be performed at home, but in this article we focus on the most common in the United Kingdom, hospital-based hemodialysis. This typically involves coming in to the hospital 3 times a week, for 3 to 4 hours

of treatment. In this article, we report results from a series of focus groups held as part of a U.K. study into facilitating self-management among people on hospital hemodialysis. As little work in this setting exists, we aimed to explore the views and experiences of hemodialysis unit staff members and patients on the meaning of self-management. We discuss a core theme that emerged from the findings: the metaphor of the hemodialysis unit as a family.

Background

Researchers and scholars have defined self-management in a number of ways. This term sometimes refers to an individual's adherence to a prescribed treatment regimen, or "compliance" (Costantini, 2006). This is often the prevailing biomedical view (Tattersall, 2002). Researchers in medical sociology have long taken a broader view, characterizing self-management as the ability of the individual to manage his or her condition and treatment in the context of his or her whole life. Practitioners in organizations such as the U.K. Health Foundation have also increasingly realized that self-management must be supported by responsive clinicians and a health care system that enables self-management (Health Foundation, 2008a, 2008b).

Health professionals encourage a person on hemodialysis to perform a number of tasks to stay as healthy as possible. In the United Kingdom, hemodialysis typically takes approximately 3 to 4 hours per session, 3 times a week. This requires the patient to travel to a hospital or satellite unit, often via hospital transport, which can include significant waiting times. A patient will interact with a number of other patients in the waiting room on each visit to the unit, and, during hemodialysis, health professionals will situate that patient in a chair or bed surrounded by a number of other patients.

Between hemodialysis sessions, patients will see a number of members of a multidisciplinary team, including clinical support workers, nurses, doctors, and dieticians, as well as counselors, if necessary. On “dialysis days,” patients frequently report feeling too drained or disoriented to do any other daily activities after their session. Health professionals prescribe many types of tablets, some of which have to be taken in the morning and some with food throughout the day. They also limit fluid intake from all sources, including food, often to as little as 500 ml a day. They restrict use of foods and drinks high in substances that are difficult to remove by hemodialysis (such as phosphorus or potassium). They recommend “against” many more foods and drinks than they “allow.” Examples of foods to avoid include bananas, whole meal bread, mushrooms, and coffee (Hollingdale, Sutton, & Hart, 2008). Malnutrition is a risk in this patient group, partly because health professionals restrict intake of “healthy foods,” such as vegetables, fruits, whole grains, and lentils, because of their potassium content.

Studies of self-management take many forms. Quantitative assessments are common in conditions such as diabetes (Norris, Lau, Smith, Schmid, & Engelgau, 2002; Warsi, Wang, LaValley, Avorn, & Solomon, 2004), looking at adherence to treatment, self-management behaviors, and self-efficacy (an individual’s confidence in his or her ability to successfully perform a given behavior). As most self-management programs constitute complex interventions, qualitative methods often serve as an important part of the evaluation, particularly to understand patient perspectives (Anderson, 2008).

Evidence increasingly shows that a “whole systems” approach that includes patients, clinical and support staff, management, and policy makers is required to have any impact on the extent to which people with chronic conditions self-manage (Greenhalgh, 2009). However, a paucity of work exists on self-management in ESRD, especially regarding people on hospital

hemodialysis (Novak et al., 2013). In this article, we report the initial phase of the “SELF-Management and Dialysis Evaluation” (SELFMADE) study. We aimed to explore patient, caregiver, and staff perspectives of self-management in hospital-based hemodialysis.

Methodology

In the SELFMADE study, we followed an action research design (Hart, 1995), whereby a cycle of acting to engender change is undertaken while continuously evaluating the impact of these actions. Our method was informed by the theoretical assumptions of cooperative inquiry Heron and Reason (2001) described. This brings together people who have similar concerns and interests to understand the situation, develop new and creative perspectives and strategies, and learn how to act to change and improve a situation. The SELFMADE study united as co-researchers, patients, clinicians, and researchers (see Figure 1). Heron and Reason identify four stages of cooperative inquiry as follows:

1. Co-researchers come together to explore an agreed on area of activity.
2. Co-researchers also become co-subjects, engaging in the actions they have agreed on and observing and recording the process and outcomes of their own and each other’s actions and experiences.
3. Co-subjects become fully immersed in and engaged with their actions and experiences.
4. Co-researchers come back together to share findings and experiences and consider their original ideas in light of these.

INSERT FIGURE 1 ABOUT HERE

Following initial discussions among patients, clinicians, and researchers who identified the need to work toward a culture of self-management, the focus groups we describe here formed part of the second stage of cooperative inquiry, with the purpose of informing a change toward a self-management culture through the development of a nurse facilitator role. Following National Health Service (NHS) Ethics and Governance approvals, we employed a mixed methods approach, along with a range of documentary analysis, focus groups, interviews, and quantitative measures, such as psychological questionnaires and clinical outcomes. The project necessitated lay involvement, with patients involved in project management (four were members of the project steering group responsible for overall project governance) acting as partners in various study work streams and attending “collaborative groups,” where clinical staff and patients work together on the project. Activities in the collaborative groups included contributing to data analysis through discussion and interpretation of emerging themes.

We held six focus groups across three hemodialysis units. We organized one patient and one staff focus group at each site. A semi-structured discussion format allowed for consistency of core themes, as well as the flexibility to explore relevant issues important to respondents. We chose focus groups to allow patients and staff members to share a variety of opinions and for other patients and staff members to comment on those opinions. Patients and staff attended separate focus groups to encourage a more frank discussion of issues where fear of negative repercussions might otherwise limit openness (Kitzinger, 1995).

Participant Selection

We used a purposive sampling technique to ensure a wide range of participants in the focus groups (Gobo, 2004). Factors taken into consideration when determining the range of patient

participants included age, sex, number of years on hemodialysis (in other words, how “experienced” they were as renal patients), and ethnicity. The primary consideration when sampling staff participants was ensuring that a range of roles and levels of seniority were represented.

A total of 15 participants took part in the patient focus groups (including a caregiver), and 15 participants took part in the staff focus groups. Of the 15 patients, 5 participated at site 1, all women, with a mean age of 51.6. Four patients participated from site 2, 3 of whom were women, with a total mean age of 54.5. Six patients participated from site 3, including 3 women, with a total mean age of 65.7. Staff roles are detailed in Table 1. In addition, once we had coded the findings and derived themes, we undertook vicarious respondent validation (Creswell, 2012) specifically through facilitated discussions with a further 8 patients and 30 staff, purposively sampled from people who could not attend focus groups. This ensured a full range of perspectives and confirmed the thematic coding.

INSERT TABLE 1 ABOUT HERE

Focus Group Setting

We conducted each focus group at the site at which patients visited and staff worked. This ensured minimum disruption to patients and staff. We used a quiet private room at each of the three hospitals. Site 1 was the lead unit, where the nephrologists for the area worked and inpatient hemodialysis was provided for those who needed it. Sites 2 and 3 were “satellite” units nephrologists visited on a less frequent basis. Sites 1 and 3 were comparable in size and level of activity (24 beds or chairs in each unit). Site 2 was smaller (18 beds or chairs). Differing requirements for different service users entailed a mixture of beds and chairs.

Each unit typically had three to four “shifts” of people dialyzing per day, resulting in approximately 60 to 100 people dialyzing at a given site on a given day, over the course of approximately 14 hours. Most of these people will undergo dialysis 3 times a week, either on Monday, Wednesday, and Friday or Tuesday, Thursday, and Saturday. Consequently, the same group of people usually experienced dialysis together each time they visited, and each unit had a communal waiting room, where a lot of discussion and communication between service users took place.

Data Collection

We conducted the focus groups in 2012. Using a standardized topic guide (see Table 2), two of the four members of the qualitative research team (PMW, MO, JR, and RB) ran the focus groups. We audio recorded, transcribed, and anonymized the discussions, which lasted approximately 60 minutes. Patients and staff members gave written consent prior to commencement.

INSERT TABLE 2 ABOUT HERE

Analysis

We took a thematic approach to the analysis (Fereday & Muir-Cochrane, 2008). We entered transcripts into NVivo software (QSR International 2006). The entire qualitative research team participated in coding (see “Data Collection” section). We used a combination of a priori and emerging themes. We explicitly explored a priori themes in the discussion schedule, primarily “Challenges [to self-management]” and “What helps?” We each generated codes independently, coding the first transcript and then meeting to reach a consensus. We then independently coded the remaining transcripts, along with a recording of the first, and we met once again to check for consensus and reach consensus by discussion where discrepancies remained. We next organized

the codes into coherent themes, wrote them up, reported them to the study steering group, and then fed them back to patients and staff members for validation.

Findings

We identified a number of themes. We will present the differences in patients' and staff members' understandings and experiences of self-management in center-based hemodialysis and relate these understandings and experiences to the core theme of the hemodialysis unit as family.

Importance of Emotional Support

The family often serves as an important source of emotional support. In the dialysis unit, patients often exchanged emotional and informational support. Both patients and staff members viewed peer support as being beneficial to self-management. For patients, this meant giving and receiving both emotional support and information on things they found helpful. For staff members, this only held true for emotional support: "They chivvy [encourage] each other along." (Health care Professional [HCP] Site 1 [S1]). Staff members had reservations about information exchange between patients in case misinformation spread or in case patients mistakenly adopted elements of treatment specific to the individual, such as recommended fluid intake: "You tend to find sometimes too much information can be bad thing, especially amongst themselves" (HCP, Site 3 [S3])

Staff members viewed feelings of initial shock as an emotional barrier to patients' understanding of educational input. Both patients and staff focused on two elements: timing and framing. Education was a one-time predialysis initiation package:

Yeah, they're overwhelmed when they first come in...it's too much, and they take home the booklets and then the little bits they want to know, how am I going to get here, what kind of things do I have to do, all the little rules that you know to follow. The important stuff is forgotten because there's just too much to take in. (HCP, S1)

Patients highlighted issues around the predominance of negative messages. Dietary information was framed in terms of what patients were recommended to avoid:

[Dietary advice] has got to be hugely tailored, obviously. As I say, we've got different conditions. Obviously, some of us pass urine, [and] some of us don't, and that's going to have an effect on what's left in your blood and other things, so there are going to be some conditions, but I suspect they could probably break it into groups and say, you know, you're a Group A, and you're a Group F. (Patient [P], S1)

Balancing Life, Family, and Treatment

Some staff members acknowledged the difficulty of balancing the demands and nature of the treatment with the patient's everyday life: "Simple things like [not] taking the tablets...[are] a general problem, but, unfortunately, it does seem to be far more common, and that's partly because it's such a chronic and troublesome condition, to be fair" (HCP, S3).

Some patients expressed negative feelings about the treatment regimen: "Having to come here 3 times a week, I hate it, absolutely hate it" (P, S1). Patients often compensated for the perceived rigors of the treatment by rewarding themselves with "treats," which might involve some explicit balancing:

I always ask to see what my blood's doing, and, over six years, I [have come to] know what I can eat and what I can't eat. And, you know, we call it cheating. Say if I have a

packet of crisps [chips] today, I won't have nothing else...then I'll have a bit of chocolate tomorrow, [and] I won't have nothing else [that] I shouldn't have. (P, S2)

Patients frequently stated that eating foods they enjoyed was a vital component in maintaining emotional well-being. This tension between patients' maintaining a strict regimen and enjoying the foods they wanted clearly caused strain between health care professionals and patients. The balancing went further than adjusting diet and fluid intake, extending to offsetting the impact of hemodialysis on home life: [Patients] "think, well if I can shave off half an hour here [time on dialysis], I'm going to get home half an hour earlier, so I might just get in time to put [my children] to bed" (HCP, S1).

Good Patient/Bad Patient

Despite the policy shift toward partnership between staff members and patients (Clark et al., 1995; Rummery, 2009), staff members were more likely to view self-management through the lens of "compliance." Moreover, they viewed patients who followed HCPs' instructions in a positive light: "Some patients turn up beautifully, religiously, never miss a session. It's because they're very, very fastidious, and those ones would be perfect for encouraging self-care because they're conscientious and involved" (HCP, S1).

By contrast, staff members talked about patients they viewed as "noncompliant" in chastising parental terms: "They don't hear, no matter how many times we tell them" (HCP, S1). Patients also seem to have internalized some of these messages: "I'm dreadful taking tablets. I'm dreadful. I've got to take phosphate binders. My phosphate is very high, and my potassium very high. I'm not an ideal patient, to be honest" (P, S3).

When discussing staff attitudes toward adherence, patients frequently used terms such as “naughty” and “cheating.” For example, one stated, “Although [staff members have] said [dietary nonadherence is] naughty...it hasn’t made a difference” (P, S2).

Hemodialysis Unit as Family

Although patients and staff members acknowledged the importance of the patient’s family within the self-management process, they more commonly used the idea of family when describing the hemodialysis unit: “It’s like a little family I think. You know, you’re all there for the same purpose, and it helps you forget about your other problems” (P, S3). This sentiment was recognized, and apparently shared by HCPs:

We had one [caregiver] recently, an elderly lady, [who] said, “I really feel like you’re my family.” Her daughter died, and she was so lost because she didn’t even have us. She could come in and see us, but that contact was lost. They do see us as family, and we see them as family. (HCP, S2)

HCPs and patients often stressed the social and emotional support the hemodialysis unit offers: “They may talk to other patients. There are some of these older patients [who] see [hemodialysis] as like a social outing” (HCP, S3). A patient explained:

I don’t get depressed now. I don’t do that, but it’s lonely, if you know what I mean, so now I like to go out, you know, and I like the crowd. That’s why I come here and do the [hemodialysis]. (P, S2)

Although this family dynamic seemed to help many patients, clearly the restricted autonomy resulting from being dependent on hemodialysis created ambivalence:

I don't want to go yet, right, and I'm not going to let this rule my life. I think they do all they can do for us, to be honest with you. You know, they look after us to the best of their ability...I try not to let this get to me too much, having to come here 3 times a week. I hate it, absolutely hate it, right, but the other way I look at it is if I don't come, I die. (P, S2)

Sometimes this "family dynamic" was apparent in the subtext of conversations and in the way staff members and patients thought about relationships:

[Peer pressure is] particularly a problem for the young or older children, you know, we have. I call them children because it's like we have a few patients sort of 18 to 22, don't we? We have a few patients, and they [find it] incredibly difficult to cope because, you know, they see their friends going out and about and running around. (HCP, S3)

Some patients spoke in terms of acting the child: "[I am] cheeky [to staff members], yeah, and [the staff members] let me get away with it" (P, S2). Alternatively, some older patients seemed to view staff members as their children: "The older patients are quite nice; actually they treat us as their children" (HCP, S1). However, as in all families, patients shared narratives of disagreement. In one unit, a patient complained about the radio constantly playing, so staff members removed it. Other patients then complained that one individual had curtailed their (and staff) enjoyment, so they initiated a campaign to reinstate the radio.

Discussion

Although all of the themes described above emerged in both staff and patient discussions, staff members and patients focused on different themes. Staff tended to emphasize the adherence aspects of self-management and view patients as either "good" for sticking to their treatment

regimen or “difficult” for not “complying” with treatment. Conversely, patients saw self-management as a complex balancing act between medically necessary treatment and lifestyle changes, other life demands (e.g. family, work), emotional health, and maintenance of a sense of purpose.

Given the importance of family and social support in self-management (Ryan & Sawin, 2009), the fact that the metaphor of the hemodialysis unit as family spontaneously emerged is interesting. The idea of the family as a metaphor has been found elsewhere in health care. For example, researchers conducting a focus group study of renal patients in Canada reported perceptions that hemodialysis units were at one time like a family, but had increasingly moved toward an “assembly line” model (Allen, Wainwright, & Hutchinson, 2011). The metaphor has been applied to nursing home life (Nyström & Segesten, 1996), identifying staff members as the “parents” and residents as the “children.” However, unlike with children, staff members did not expect residents to learn new skills or grow.

Metaphors are a useful way of uncovering subconscious thought and cultural discourse (Lakoff & Johnson, 1999; Sontag, 1983) and can provide direction in the development of a conceptual framework. We draw on the work of Bourdieu (Bourdieu, 1990; Bourdieu & Passeron, 1977) to develop a framework for the hemodialysis unit as a cultural field, the cultural capital contained within, and ways habitus shapes that cultural field. We then question whether Bourdieuan theory (Bourdieu, 1990) is adequate to explain the family dynamic of a hemodialysis unit in the rapidly shifting landscape of Western health care and suggest that sociological ambivalence (Connidis & McMullin, 2002; Luescher Pillemer, 1998; Silverstein, Gans, Lowenstein, Giarrusso, & Bengtson, 2010) might be usefully applied to understand

concurrent tensions within the relationships between patients and staff and the hemodialysis unit as institution.

Although extensively critiqued by proponents of the Marxist (Adler, 2011) and feminist (Kuhn, 2013) viewpoints, the functionalist definition of family continues to dominate popular and political thought (Conservative Party, 2010, Republican Party, 2004). Some view the family as serving important functions in transmitting values and norms and providing care and protection (Murdock, 1949; Parsons & Bales, 1955). Similarly, respondents spoke in terms of the hemodialysis unit's providing care and compassion and setting rules for how patients should behave. Researchers developed the solidarity model (Bengston, Giarrusso, Mabry, & Silverstein, 2002) primarily to assess current societal change on the family. This model provides a useful framework for identifying how we can interpret a typology of the family from the hemodialysis unit perspective (see Table 3).

INSERT TABLE 3 ABOUT HERE

Application of the solidarity model to the metaphor of hemodialysis unit as family illuminates the source of potential tensions between staff members and patients, particularly characterized by the description of good and bad patients frequently alluded to in our data. We can explore this further by drawing on Bourdieu's concepts of cultural fields, cultural capital, and habitus (Bourdieu, 1990, 1993; Bourdieu & Passeron, 1977). Cultural fields are a series of "institutions, rules, rituals, conventions, categories, designations, appointments and titles which constitute an objective hierarchy, and which produce and authorise certain discourses and activities" (Webb, Shirato, & Danaher, 2002, p. 2122). Although Bourdieu referred to the

educational establishment (Bourdieu & Passeron, 1977), we could arguably view a hemodialysis unit as a cultural field (see Figure 2).

INSERT FIGURE 2 ABOUT HERE

A cultural field is also shaped through the tensions between or among the main actors (in this case, staff members, patients, and the English NHS) as to what is deemed capital within the field and how this is allocated (Webb et al., 2002). Cultural capital might include material items with symbolic value or symbolic capital, such as prestige, authority, and status (Bourdieu, 1993). It might also include legitimated sources of knowledge (Atkinson, 2011) and, as such, highlights the potential tension between professional and lay knowledge (Prior, 2003; Wilson, 2001).

Respondents clearly articulated judgment over which behaviors were professionally sanctioned and those that were not. Competition for cultural capital evolves in two main ways (Bourdieu, 1993). First, Bourdieu argued that reproduction occurs, where each actor has certain expectations of the capital one is likely to gain in the field; hence, patients might expect that they will only be passive recipients of care rather than partners in care (Bourdieu, 1993). Second, transformation may occur, whereby an actor is able to increase his or her status and thus transform his or her own value and status in the field (Webb et al., 2002).

We could argue that this transformation has been occurring as exemplified by the policy discourse surrounding the rise of the autonomous, expert patient (Clark, 2003; Coulter, 2002; Department of Health, 2001, Wagner, 1998) and the move toward collaborative models of care (Health Foundation, 2008a, 2008b). However, researchers have questioned the extent to which this transformation is reality rather than rhetoric (Wilson, Kendall, & Brooks, 2006, 2007), and

further exploration of Bourdieu's thinking on how cultural fields reproduce themselves (Bourdieu & Passeron, 1977) illuminates this further.

Misrecognition and symbolic violence would result in a cultural field feeling familiar and "right" even when some actors are subjugated by others. Therefore, although collaborative approaches to care might call for a new mode of health care professional-patient relationship, patients (and staff) might feel more comfortable maintaining the dominant professional-passive patient relationship, exemplified in our data by the metaphorical imagery of staff members as parents and patients as children. Bourdieu described "illusio" and "universalization" as the tacit commitment to existing values and logic (Bourdieu, 1990); hence, although an outsider might suggest that advice around adherence in hemodialysis be adapted to ensure some reasonable balance in quality of life for the patient, for the staff, "adherence rules" tacitly govern all interactions and guide the framing of patients as good or bad.

Finally, Bourdieu (1993) discussed an inalienable culture and the market. A cultural field contains values that are spoken in terms of being above the "market," such as values of care and compassion. However, a cultural field is continuously influenced by external fields such as market forces. For a hemodialysis unit, this might mean that values around a patient-centered approach might be modified by the need to increase productivity, leading to an "assembly line" feel (Allen et al., 2011).

One of the most known concepts Bourdieu offered on how cultural fields reproduce themselves is the idea of "habitus." He described habitus as predispositions toward certain forms of action that have been shaped by each actor's cultural history and normally operates through tacit anticipation of the probable outcomes (Atkinson, 2011; Webb et al., 2002). In the health

care setting, we can see that habitus might operate as the traditional medical model for health care professionals and indeed for some patients. Likewise, people living with ESRD might also have predispositions, for example around lifestyle, that have been shaped by their own cultural history. However, habitus is not constant and can be tested by external events that challenge a person's normal repertoire (Archer, 2010). Hence, attempts to develop a culture of collaborative self-management within a hemodialysis unit might challenge both staff members' and patients' normal predispositions.

Although some have demonstrated the significance of Bourdieuan theory in illuminating health care underpinned by patient involvement (Gibson, Britten, & Lynch, 2012), others have questioned the relevance of Bourdieu's work to today's complex society. Archer (2010) argued that socialization or cultural history has less influence nowadays. The media, the Internet, and globalization have had a profound impact on the way individuals perceive the patient-HCP relationship (Coulter, 2002; Kivits, 2006; Shuttleworth, 2006), which challenges the traditional model of the dominant HCP-passive patient. In our rapidly changing postmodern society, Archer argued that habitus no longer has sufficient explanatory power. Atkinson (2011) also critiqued Bourdieu in only describing habitus at an individual level.

Reay (1998) suggested that within the school scenario are two competing habituses: the institutional and familial. In U.K. health care, this could be translated as the individual unit, hospital, or overall NHS institution habitus coinciding with the tacit predispositions and perceptions of individuals (multidisciplinary staff, managers, patients, and caregivers). Although accepting Archer's (2010) argument that habitus might be less stable in a rapidly shifting society, the findings from our study do suggest that the hemodialysis unit is a cultural field where a number of habituses come together and create tension. Returning to the metaphor of the

hemodialysis unit as family, we can usefully draw on sociological ambivalence to conceptualize this further.

Although psychological ambivalence describes simultaneous feelings of love and hate at an individual level, sociological ambivalence refers to coexisting converging and diverging normative beliefs and values (Luescher & Pillemer, 1998; Silverstein et al., 2010). In recent years, ambivalence has been used as a concept to understand intergenerational relationships between older people and their children, where despite concurrent feelings of love and hate family ties continue. The data seemed to reflect these entwined positive and negative feelings, where patients might have simultaneous feelings of positive regard for peers and staff members and negative feelings around the “rules” set for them to which they are expected to adhere and their experience of entrapment and lost time.

Staff members, too, expressed conflicting views, for although they appreciate the predicament of hemodialysis patients and establish a connection with many, staff members concurrently expressed frustration over patients’ perceived lack of adherence. Connidis and McMullin (2002) described such conflict as “an inevitable feature of the structured social relations” (p. 597). Thus, conflict within the hemodialysis unit is more the product of, for example, evidence-based medicine versus lay beliefs and preferences and the unit as service provision versus the experience of service use.

Within the family, ambivalence stems from the tension between the desire for autonomy and the need for interdependence (Silverstein et al., 2010), and, again, this is mirrored in the hemodialysis unit through the desire to be free from its constraints but a sense of total reliance on the service. Luescher and Pillemer (1998) suggested that these tensions and conflicts occur at the

levels of social structure and subjectivity, and we are able to map our data from patients to these levels (see Figure 3). The subjective experience of hemodialysis is set against a social structure where personalized care is seen as the gold standard, but resource constraints often result in an assembly line approach. The hemodialysis unit is also framed by an embedded tension between expert (clinical) and experiential (patient) knowledge of living with ESRD and a history of roles predicated on a passive patient having treatment done to them versus a gathering rhetoric of active patient involvement in care.

INSERT FIGURE 3 ABOUT HERE

If ambivalence is unsurprising and inevitable, how does this help us to move forward in developing a collaborative culture within a hemodialysis unit? Within the participatory action research methodology of the SELFMADE study, capturing both staff members' and patients' perspectives has enabled us to collaboratively explore tensions and differing perspectives about the purpose of self-management. Previously, the success of self-management initiatives has been understood in terms of improving adherence or increasing self-efficacy. However, this is an outcome determined by the system (institutional habitus) and not the patient (familial habitus). As SELFMADE developed, we set up a number of collaborative work streams (to be reported elsewhere) that moved beyond the adherence-self-efficacy perspective and included, for example, ways of reducing time at the unit (coordinated outpatient clinics and improved transport service) and facilitating ways for patients to take holidays.

Cultural fields, capital, literacy, and habitus provide a way of conceptualizing what needs to be done in terms of strategic thinking (Webb et al., 2002) to move toward a collaborative culture within the hemodialysis unit. This includes an understanding of each actor's position and

resources within the cultural field and an awareness of the rules, values, and cultural capital each person brings to the cultural field. Within this cultural field, we must understand how a medical focus toward hemodialysis is hybridized and reinterpreted (Dew et al., 2013) by people's living with ESRD. Finally, the unit as a whole (staff members, host organization, and patients) needs to be able to maneuver and negotiate as well as possible (Webb et al., 2002) the barriers to collaborative work.

Limitations

Health researchers widely employ focus groups, as they can be highly effective in gathering a variety of viewpoints and particularly gaining data on interactions between peers. However, as with any methodology, focus group findings must be interpreted in light of what they can and cannot tell us. In focus groups, consensual discussion is not necessarily the individual patient view (Lehoux, Poland, & Daudelin, 2006). Focus groups can tell us about interactions and can develop a consensus, but they can also create ambiguity, and participants can come out with different views from those they held before joining.

It should also be noted that although the hemodialysis unit has been treated as a homogenous entity during this article, subtleties exist, such as the fact that different patients hemodialyze in different 'shifts' throughout the day and on different days of the week. Similarly, staff members work on various days, so some family members will be more proximal to each other and some more distal. This can be viewed as analogous to an "extended family." This could be a subject for further investigations into the culture of the hemodialysis unit.

Conclusion

Patients and staff members in the hemodialysis units discussed similar themes in focus groups around their understanding of, and facilitators and barriers of, self-management. In particular, the theme of the hemodialysis unit being like a family emerged from the discussions. Researchers have noted this metaphor previously in the literature, but they have never closely examined or theoretically developed it within the hemodialysis setting. By drawing on the work of Bourdieu (1990, 1993), we have conceptualized this further by exploring the hemodialysis unit as a cultural field and reframing sociological ambivalence as an opportunity to work toward a culture of collaborative care.

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Author Biographies

Patricia M. Wilson, PhD, RN is a professor of primary and community care at the University of Kent in Canterbury UK.

Jonathan D. Reston, MSc, MBPsS, is a research fellow in psychology at the University of Hertfordshire in Hatfield UK.

Rebecca Bieraugel, RN, is a clinical research specialist in East & North Hertfordshire NHS Trust, UK.

Maria Da Silva-Gane, MSc, is a renal counsellor in East & North Hertfordshire NHS Trust, UK.

David Wellsted, PhD, is a senior lecturer in psychology at the University of Hertfordshire in Hatfield, UK.

Maxine Offredy, PhD, is a reader in primary health care at the University of Hertfordshire in Hatfield, UK.

Ken Farrington, MD, FRCP, is a consultant nephrologist in East & North Hertfordshire NHS Trust and a professor and associate dean of postgraduate medicine at the University of Hertfordshire in Hatfield, UK.

Table 1: Description of Staff Focus Group Participants

* 'Band' is the level of pay and responsibility used in the NHS. Higher bands equate to higher levels of seniority.

Site (Staff)	Number of participants	Job descriptions
1	7 (6 female)	2 clinical support workers, 1 band 6 nurse*, 1 social worker, 1 renal physician, 1 pharmacist, 1 housekeeper
2	4 (3 female)	1 band 5 nurse, 1 band 6 nurse, 1 administrator, 1 consultant renal physician
3	4 (4 female)	1 band 5 nurse, 1 band 6 nurse, 1 band 7 education nurse, 1 band 8 ward sister

Table 2: Focus Group Topic Guide

Patient and caregiver focus group guide	Health care professional focus group guide
<p>In your experience, what are the important things to remember in looking after yourself when on dialysis?</p>	<p>Self-management is a term commonly used in different situations and might mean different things to people. Can we start off by sharing what the term means to each of us?</p>
<p>If not raised in discussion, ask for their opinions on how important the following are:</p> <ul style="list-style-type: none"> Fluid intake Diet Medications Exercise Mental well-being 	<p>If we define self-management as patients’ managing their condition and dialysis within the context of their whole life, in your experience, what are the important things for self-management in patients on dialysis?</p>
<p>If you had to rank all the things you have talked about, what would be the top two in terms of importance?</p>	<p>If not raised in discussion, ask for their opinions on how important the following are:</p>
	<ul style="list-style-type: none"> Fluid intake Diet Medications Exercise Mental well-being
<p>Thinking about some of the things you think are important when looking after yourself, what are some of the difficulties you face day to day?</p>	<p>If you had to rank all the things you have talked about, what would be the top two in terms of importance?</p>
<p>If you had to rank the difficulties you have spoken of, what are the two most difficult?</p>	<p>Thinking about some of the things you think are important in self-management, what are some of the difficulties patients face in keeping to these?</p>
<p>Currently, what kind of things do you find help you to look after yourself?</p>	<p>If you had to rank the difficulties you have spoken of, what are the two most difficult?</p>
<p>Do you think that there is anything your health staff could do to</p>	<p>Currently, what kind of things do you find patients do to help themselves</p>

help you that they are not already doing?

Is there anything else that could help you look after yourself better?

Is there anything else you would like to say about taking care of yourself when on dialysis?

self-manage?

What do you think your role is in helping patients to self-manage?

How do you gauge whether a patient wants to self-manage or be involved in his or her care?

Do you think that there are any things you could be doing that you are not already to help your patients self-manage?

Is there anything else that could help patients look after themselves better?

Table 3: Solidarity Model Applied to the Hemodialysis Unit

Dimensions of the family	Application to the hemodialysis unit
Associational	
How often family members see each other	Patients spend around 1012 hours per week within the unit
Functional	
How members of the family help each other	Within the traditional medical model of care, patients are receivers of care from a professional workforce
Consensual	
How members of the family agree with each other	Patient-HCP agreement depends on congruence between beliefs and values
Affectual	
How members of the family care for each other	Perceptions of compassion and care depend on patient and HCP's beliefs and values
Normative	
What values they share	HCPs' values can be placed on a continuum from paternalistic to collaborative to patient-led care. Patients' values might also vary accordingly
Structural	
How far family members live from each other	Dialysis units serve a local population, but inevitably journey times and ease of access vary for each patient

Figure 1: Application of cooperative inquiry within the SELFMADE study

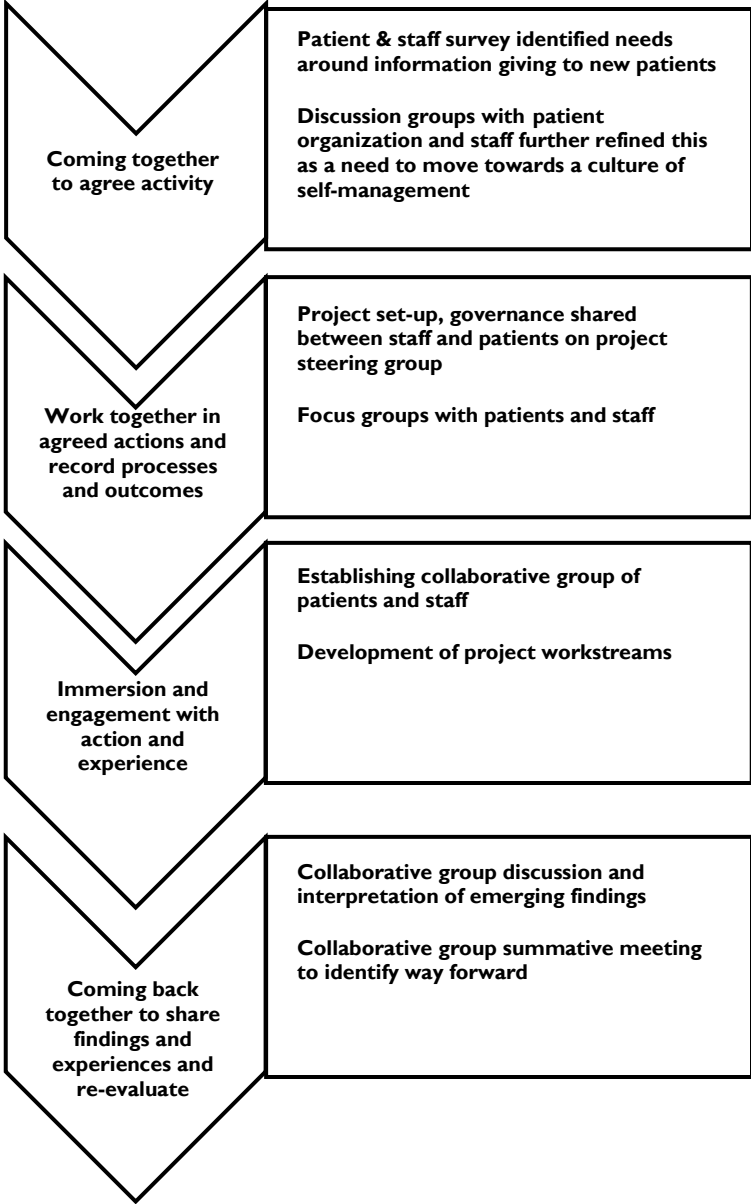


Figure 2: Hemodialysis unit as a cultural field

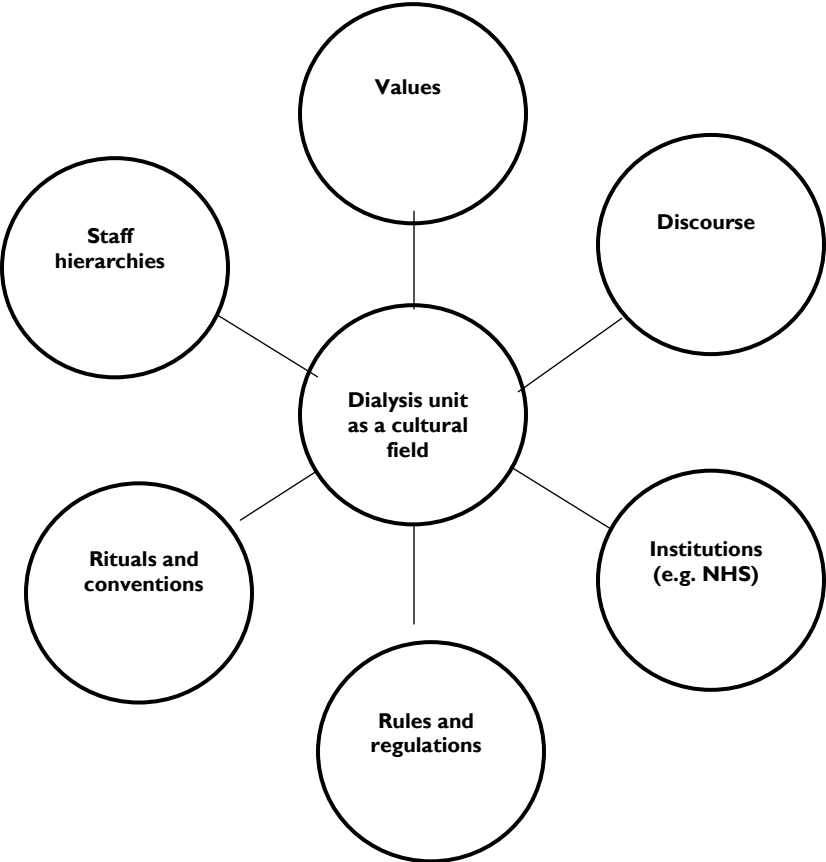


Figure 3: Sociological ambivalence – the hemodialysis patient perspective

