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Title: Compliance, normality and the peritoneal dialysis patient

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COMPLIANCE, NORMALITY AND THE PERITONEAL DIALYSIS PATIENT

Abstract

Monitoring and enhancing patient compliance with peritoneal dialysis is a recurring and problematic theme in the renal literature. There is also a growing body of literature that argues that a failure to understand the patient perspective of compliance may be contributing to these problems. The aim of this study was to understand the concept of compliance with peritoneal dialysis from the patient perspective. Using the case study approach recommended by Stake (1995), five patients on peritoneal dialysis (PD) [Author Query/Revision Request: NNJ adheres to the APA guidelines for unbiased language, so, for example, we use the term "patients on dialysis" rather than "dialysis patients." Please change to unbiased language throughout the manuscript.] consented to in-depth interviews that explored the meaning of compliance in the context of the PD treatment and lifestyle regimens recommended by health professionals. Participants also discussed the factors that influenced their choices to follow, disregard or refine these regimens. The results indicate that health professionals acting in alignment with individual patient needs and wishes, and demonstrating an awareness of the constraints under which patients operate and the strengths they bring to their treatment, may be the most significant issues to consider with respect to definitions of peritoneal dialysis compliance and the development of related compliance interventions. Aspects of compliance that promoted relative normality were also important to the participants in this study, and tended to result in greater concordance with health professionals' advice.

COMPLIANCE, NORMALITY AND THE PERITONEAL DIALYSIS PATIENT

Introduction

Monitoring and enhancing patient compliance with peritoneal dialysis (PD) is a recurring theme in the renal literature (Kutner, 2001; Kutner, Zhang, McClellan, & Cole, 2002; Logham-Adham, 2003). These concerns about compliance are valid, for whilst robust statistical data on PD compliance are extremely difficult to obtain, there is good reason to believe that anywhere between 13% and 50% of patients on PD do not comply with their prescribed treatments (Kutner, 2001; Raj, 2002). Reasonably strict adherence to PD treatment regimens is essential because the personal consequences of non-compliance for the PD client, which may include peritonitis, sepsis, cardiovascular morbidity, transfer to haemodialysis, and death, also have implications for renal care providers in terms of increased costs of care (Kutner, 2001; Kutner, et al., 2002; Logham-Adham, 2003). Unfortunately, research that investigates rates of compliance, or interventions to improve compliance with PD, has furnished equivocal outcomes (Costanini, 2006).

It has been argued that a factor contributing to both the imprecise data on PD compliance rates, as well as the apparent failure of compliance interventions, is that the concept of 'PD compliance' on which many of these studies is based is either non-existent, or inadequately defined (Richard, 2006) (Gascon, Sanchez-Ortuno, Llor, Skidmore, & Saturno, 2004; Kutner, 2001). This is despite the development of PD

outcome measures such as the KDOQI guidelines (Kidney Disease Improving Global Outcomes (KDIGO), 2008), ANNA Standards of Care and Clinical Guidelines for PD adequacy (American Nephrology Nurses' Association (ANNA), 2005), and the CARI Guidelines in Australia (Kidney Australia, 2005) [Author Query/Revision Request: Reviewers suggest that you consider including the existence of recommended PD outcomes measures such as the KDOQI guidelines and ANNA Standards of Care and Clinical Guidelines for PD adequacy.]. From this viewpoint, definitions of compliance are not yet of the rigour required to form the basis of empirical studies and to furnish reliable data. A more recent criticism (Cook & McCarthy, 2007; McCarthy, Cook, Fairweather, Shaban, & Martin-McDonald, 2009) [Author Query/Revision Request: need authors for these] is the tendency of existing PD compliance definitions to emphasise the clinical imperatives of health professionals over the personal imperatives of the patient . From this perspective, PD compliance studies are unsuccessful because their operational definition of compliance, where it exists, actually ignores the patient. It follows that if the very definitions on which compliance studies are based are so unmindful of the patient's perspective, interventions to enhance compliance are bound to fail. Indeed, before we undertook this study, an exhaustive search unearthed only one PD paper that had explored the subjective notion of compliance from the patient's point of view (Curtin, Johnson, & Schatell, 2004). So despite the extensive literature on compliance, the voice of the renal patient in this body of research (who is, after all, the focus of compliance interventions) is noticeably absent. Given the rapid increase of client-managed PD worldwide, it is timely that the concept be revisited, and that in particular, we honour the PD client's pivotal role in this concept.

This study explored the meaning of compliance from the perspective of patients on PD. It also explored the factors that influence renal patients' choice and ability to follow, disregard or refine PD regimens to accommodate their own lifestyle expectations and the challenges inherent in undertaking PD in their specific life contexts. Hence the research questions for this study were twofold:

1. What does compliance with PD treatment and lifestyle regimens recommended by health professionals mean to patients on PD?
2. What factors influence the choice of patients on PD to follow, disregard or refine these regimens to accommodate their own lifestyle choices?

STUDY DESIGN

Methodology

This qualitative investigation was undertaken according to the case-study approach recommended by Stake (1995a). [Author Query/Revision Request: Reviewers suggest adding further description of the Stake approach.] Generally speaking, a case study is “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly understood” (Yin, 1994, p. 13). Case studies are used to probe deeply into a phenomenon to gain insights into a complex area that is new, not understood, or unexamined. Case studies can provide a powerful story to illustrate a particular social context or phenomenon (Grbich, 1999). In doing so, case study methods require the researcher to understand the case in context where information about the case and its context are collected over considerable time and following considerable engagement.

The aim is to achieve internal consistency and meaningfulness of the information rather than to undertake a comparison to theories or expectations (Carroll & Johnson, 1990).

For this study, Stake's approach according to Stake (1995b) was used because it best suited the inquiry. According to Stake, a case is a "specific, unique, bounded and integrated system with working parts"(1995b, p. 7). Stake argues that in case study "we study a case when itself is of very special interest. We look for the detail of interaction within its contexts. Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances." (1995b, p. xi). This was an ideal approach as we were interested in understanding how patients function in their ordinary pursuits and contexts, and where the research begins with a willingness to put aside preconceived notions of what concepts such as PD compliance might be. The advantage of this approach was that an understanding could be developed of phenomena and how the patients' compliance works at very specific, local levels. A *collective instrumental case study* approach was adopted, whereby renal patients and their notions of PD compliance were considered the fundamental "working parts" (1995a, p. 7) of a specific, unique, bounded but integrated healthcare system. The strength of this approach is that it produces an in-depth understanding of PD compliance in the context in which it is operating. This design enabled what Stake (1995a) described as a "particularisation of the *issue* of interest"; whereby specific renal patients' accounts of compliance and the factors that influence this aspect of their personal PD practice are thoroughly mapped and interpreted. As a balance, the views of renal health professionals to PD compliance are reported elsewhere (McCarthy, et al., 2009)

It is important to note that, in keeping with the philosophy of qualitative research, whilst the findings of such a small study cannot be generalised to every other patient on PD, many of the factors identified here may warrant consideration in other PD settings. Notwithstanding, this study produces understandings of events and phenomena at a local level (Carroll & Johnson, 1990), where it “particularises” (1995b, p. 8) notions of compliance amongst peritoneal dialysis patients. Stake argues that “the real business of case study is particularization not generalization. We take a particular case and come to know it well, not primarily as to know how it is different from others but what it is, what it does. There is emphasis on uniqueness, and that implies knowledge of others that the case is different from, but the first emphasis is on understanding the case itself” (1995b, p. 8). Thus, the strength of this study is that it produces understandings of events and phenomena that are at the local level.

Australian . [Author Query/Revision Request: Reviewers noted that this appeared to be too small a study for this generalized statement to be made and suggest that it be reworded.]

Sampling and recruitment strategy

The study was conducted within the ambulatory dialysis clinic of a large metropolitan hospital in Australia. The inclusion criteria for the study stipulated that participants must be able to understand and speak conversational English. They must also have commenced any form of PD (eg manual, automated, or continuous) at least six months prior to the study; manage it competently at home in the opinion of their health professionals; and most importantly, were chosen for inclusion by their renal nurses because those nurses considered them compliant . [Author Query/Revision

Request: By what criteria?]These criteria ensured participants were familiar with the PD procedures and lifestyle expected of them and could discuss it with confidence and authority. Individuals who lacked capacity to provide consent, suffered significant intellectual or cognitive disabilities or a comorbidity that might affect their cognition or ability to undertake home PD as recommended, such as dementia, arthritis, or clinical depression, were excluded. Purposive sampling methods were used in this study; hence of the 105 patients treated by the clinic at the time of the study, 20 clients met the inclusion criteria in the opinion of the registered nurses caring for them and were posted a letter of introduction explaining the study. [Author Query/Revision Request: How many were eliminated by a)their self-assessment of non-compliance, b) the nurses' assessment of non-compliance, c) the capacity issues, d)comorbidities, and e)other?]Five of these responded to the invitation to participate in the study, essentially becoming the self-selected 'intrinsic cases' described by Stake (1995). [Author Query/Revision Request: How were the 5 selected?]

The study was approved by the Human Research Ethics Committees of the employing University of the researchers, and the hospital from which the participants were recruited

Procedures for data collection and analysis

Each participant was interviewed for a minimum of two hours, at a time and place convenient to them. The stem questions that guided the interviews were developed from the literature review, were:

1. How did participants understand the term 'PD compliance'?

2. What did participants believe influenced their ability to follow, disregard or refine health professionals' advice with respect to PD?
3. What did participants believe could enhance PD compliance?

[Author Query/Revision Request: Reviewers ask that you include how the questions were developed.]

Consistent with the original research questions and Stakes's (1995) approach to case study, the data were immediately transcribed and thematically analysed according to: the participants' interpretations of compliance; aspects of compliance such as their choice or ability to follow, disregard or refine PD regimen; the challenges they encountered in adhering to their regimen; and the factors that enhanced PD compliance. Stake's (1995a) sequential analytic methods of categorical aggregation and direct interpretation, correspondence and pattern, and naturalistic generalizations were undertaken. Where queries arose during the analytic process, the participants were re-interviewed to verify, augment or refute the researchers' interpretations.

FINDINGS

Participant characteristics

The participants, two of whom were female and three of whom were male, ranged in age from 48 to 85 years at the time of interview. One had completed university education. [Author Query/Revision Request: Finished?]The causes of their renal failure included phenacitin-induced nephropathy, focal and segmental glomerulosclerosis, renal malignancy and glomerulonephritis. Most had experienced progressive renal failure for between 3 and 5 years from diagnosis before its severity required renal replacement therapy. Hence, all the participants stated they were aware of, and prepared for, the eventual need for PD from the time their renal failure was

recognised. Only one participant was a candidate for renal transplantation, meaning that PD was a permanent reality for most of them.

Generally, the older they were at diagnosis, the longer it took the participants to learn the procedure. Terry, [Author Query/Revision Request: Please change names to non-identified names – i.e., Patient 1 or Mr. T.]who was the youngest, took less than a week to manage it independently at home; the remainder took up to 6 weeks. At the time of interview, the participants had practised PD for anywhere between 8 months and 7 years. An indication of their level of ‘compliance’, which is often regarded by health professionals in our experience as the absence of episodes of peritoneal infection (McCarthy, et al., 2009) [Author Query/Revision Request: Please insert citation.] , is that only one participant had ever experienced peritonitis in the seven years she had practised it. None had been hospitalised after PD commencement for any other feature of compliance, such as severe hyper- or hypotension, that health professionals have discussed in our previous research (McCarthy, et al., 2009).

[Author Query/Revision Request: Reviewers suggest that you include the benchmarks with citation(s).]

Defining compliance

No participant actually used the words ‘compliance’, ‘adherence’ or any other term that health professionals might employ during their interviews. They also didn’t interpret it in the ways outlined in the literature, such as normotension or strict adherence to aseptic technique. For them, compliance with the PD regimen tended to be a matter of necessity that enabled them to cope with a life-threatening condition. There was a stoic recognition that health professionals don’t recommend PD practices

needlessly, and that one could die if their recommendations were not generally observed. Nancy for example, who articulated a great deal of fear about her kidney failure and the possibility of death throughout her interview, bluntly stated:

Nancy: ... that's what's good for me ... it's keeping me alive. I'm still frightened of the future, you know, I know I will never get well. I never will be, I will have this for the rest of my life and ... it's always there.

I: Can you tell me what frightens you?

Nancy: The future, the future, well there is no future. No kidneys – you just drop dead.

Margaret on the other hand, noted that from childhood she had been taught to acknowledge the authority of the health professions and recognise that they have her best interests at heart. For example:

Margaret: Well I take the attitude now they're the professionals, they know what they are talking about, they know what's best for you, you know, and why not follow their advice? ... I mean they make it very simple for you. ... I think they go into great detail and um, they more or less put it to the attitude now, this will help you, this is the best way to do this, and I think that is very helpful and as I say, they know what they are talking about ... I know I've got to do it if I want to live, I've got to do it, that's all there is to it ... [it] could be that I've accepted it, you know, that I've got to [as] it's the only thing that got to be done. It's got to be done and that's all there is to it. What's the sense of rebelling against it, you know?"

A common thread in all the interviews was that correctly performed PD is necessary in order “to live” (Margaret) and to “look and feel more normal” (Terry). It is *normal*

to privilege life and health over death and illness, hence compliance to ensure life and health is normal and natural too. Joseph refined the notion of normality in the most interesting way, equating his “proper” performance of PD [Author Query/Revision Request: Earlier in the manuscript, it says that none of the patients used the term ‘compliant.’ Please clarify.] with the enhancement of both his sense of being special and paradoxically, his equivalence to ”normalpeople”:

Joseph: I think I am special in some ways because a lot of people would give in with my problem ... but you have to accept when you get something bad, that normal for you isn't what it is for other people. In PD people, I am normal, in others I am not. ... I've always noticed I am different to other people because I have skin problems and allergy problems, but when I've been doing my PD and look normal among normal people I don't feel really different, because they can't see my catheter [and they] don't know about my skin.

All of these aspects of normality raised by participants - of the rightness of struggling for life, of striving to look and feel more healthy and more like other people, and of subsequent compliance with recommended PD practices to ensure this - are central to these data, and their significance will be explored in further detail in the Discussion section.

Manifestations of strict compliance

In terms of risky habits to PD such as smoking cigarettes and drinking alcohol (Kidney Health Australia, 2009)[Author Query/Revision Request: citation?], all but one participant smoked heavily prior to diagnosis, and all gave it up completely on their own initiative when diagnosed. All of the three men in this study drank beer

frequently before the onset of their kidney failure, and only one now drinks the odd light ale. All participants attended their 4 to 6-weekly clinic appointments as recommended, where their vital signs and blood levels were monitored, and adjustments were made to their PD regimen accordingly. The participants were appreciative of the care and concern of the health care team during these appointments, but in general, they tended to take more notice of the advice of Registered Nurses than medical officers. As Dan noted, “my ears are pricked all the time when the girls are talking to me”. The participants attributed this to the nurses’ more prolonged contact with them, including home visits, and their subsequent perception that nurses were more attuned to patient needs and the context in which their lives were lived.

Aside from clinic appointments and following the recommended high protein, high fibre diet (which tended to be their natural habit before kidney failure), the area where participants adhered almost religiously to health professional advice was the sterile technique necessary to avoid peritonitis. For example, all of the participants had a room in their house especially quarantined for PD; all could recite sterile procedures exactly; and all understood why such procedures were necessary. Although only one participant had experienced peritonitis, which is often a dangerous result of contamination during the PD procedure, her fear of developing it again had the effect of intensifying her adherence to recommended practice:

Nancy: ... because I couldn’t work out why it should happen ... because I had always been so, so, careful. But they never knew why [she developed it]. It is very painful and you are very, very sick. [So] you must wash, you must wash, you must wash ... I’m so extra careful.

Refinements to PD regimen

While participants stated that they never deviated from the prescribed sterile technique, other aspects of the recommended regimen were clearly open to interpretation even by these self-identified ‘compliant’ patients. The refinements fell into two categories: those that obviated the adverse effects of kidney failure or PD, and those that sidestepped procedures they couldn’t see the point of performing.

Refinements to automated PD fell in the first category. Two participants (Dan and Terry) performed automated dialysis overnight, but often found that the kinking of the catheter caused by movement in sleep tended to set off the alarms and disturb their rest. In someone experiencing the constant fatigue typical of kidney failure, this is obviously problematic. Dan’s usual solution was to simply turn off the machine, disconnect his catheter, and perform a manual exchange of dialysate the next morning rather than fix the problem immediately. Terry on the other hand refined the way his catheter was secured, allowing it, in contraindication of advice, to move more freely so that it didn’t interrupt the function of the machine:

Terry: ... I’ve [also] learnt that if you tape your tube down towards your groin ... and only just have the one tape instead of the two, your alarm goes off a lot less because it’s not kinked so much [and] because it’s in the middle there and it sort of moves around a little bit, and has that freedom to get around.

Joseph also noted problems with securing the catheter, chiefly because the tapes used to do so caused him severe skin irritation. His subsequent solution to secure the catheter was to avoid tape altogether and strategically place his trouser belt over it

when dressing. While this allowed his skin to ‘rest’, this practice did allow some movement of the catheter and sometimes resulted in trauma and pain at the catheter exit site, which he understood opened him to the risk of peritonitis.

The most significant of the procedures participants refined related to daily measurements and recording of weight and blood pressure, and alterations of prescribed medication regimens. Our experience with renal clinicians in several units [Author Query/Revision Request: in your unit? Please clarify.] indicates that they consider daily weighs and blood pressure extremely important, as they allow patients to adjust their dialysis fluid and some of their medications according to changing but objective physiological parameters. Clinicians also consider this is one area where patients are clearly remiss. These data provide justification for this observation, for with the exception of Nancy, who had kept a meticulous daily log of her weight, blood pressure, medications and dwell characteristics for seven years, the participants tended to disregard this well-meaning advice. They measured these parameters weekly or biweekly, if at all. Further exploration of why this should be revealed that subjective parameters – swollen feet, racing heart, headaches, lassitude – were more accurate indicators for the patients that their dialysate or medications needed adjustment. Margaret explained how she had once strictly followed the advice of renal clinicians in this regard, but felt over the seven years of her PD practice that it was redundant:

Margaret: I’m afraid I’m skipping it a bit now ... they always take the blood pressure and the weight when I go [to the clinic] anyhow [and] well, when it was everyday and I thought, oh this is a bit much. And I said to them ‘do I

have to do it every day,' and they said 'not really'. So I have dropped to about once a week now.

Interviewer: So you have developed a real feel for how your body's reacting to everything?

Margaret: Well that's right. I'll know if I'm not up to scratch [if] I start to feel lethargic and um, not interested in food and things like that.

Similarly, although participants considered that they performed PD well, they often changed the dose or frequency of their adjuvant medications according to their subjective symptoms rather than the objective signs taught them in the clinic[Author Query/Revision Request: Reviewers commented that this does not seem to be consistent with compliant behavior and asked that you clarify.]. However, they tended to negotiate changing medications more often with their treating team than they did blood pressure and weight recordings.

Deliberate non-compliance

Outright disregard of health professionals' advice was rare. Terry, for example, was prescribed a minimum of 18 medications per day, and was extremely well-informed about the actions and the side effects of all aspects of his PD treatment. One of the side effects of treatment is extreme constipation, which should ideally be avoided in these patients as it increases the risk of peritonitis. Terry was aware of this, yet for the sake of relatively normal social interactions, refused to take any laxatives to counter this:

Terry: If I do I've got to be careful how I cough, how I sneeze ... ridiculous. For the amount of inconvenience [constipation causes], I'm quite prepared to put up with that rather than have a life of diarrhoea and haemorrhoids ... Left to my own devices I do pretty well.

In some units we have worked in, patients on PD are advised not to have pets [Author Query/Revision Request: This is not the experience of the reviewers, so need to clarify if this is the practice of this particular unit.], as they are believed to spread infection and dislodge catheters if they become too boistrous. Nonetheless, of the five participants, two were extremely attached to their very active small dogs, which sat on their laps during interviews and also slept with them at night, while another regularly cared for her son's dog.

Challenges to compliance

PD is a very prescribed regimen, necessitating great discipline, attention to detail and many restrictive lifestyle changes. Participants indicated that the level of discipline and concentration required can be difficult to master in the context of a condition that is characterised by overwhelming fatigue. For example renal patients, who generally experience problems with calcium and vitamin D uptake, are advised to undertake moderate exercise daily to counter the effects of this on their bone density and to keep their body mass index within the healthy range. All participants commented on how hard it was to exercise as recommended when they were so permanently weary, and often had co-morbidities such as arthritis or gout that inhibited their activity even further. Fatigue was also significant in terms of restricting social activity and normal activities of daily living, such as shopping and housework. In addition, while it was

theoretically possible for all of them to arrange for the vast amount of PD equipment they needed for even a few days to be transported to a potential holiday location, the energy and logistics involved in doing so were so off-putting that only one participant had ever taken a vacation. As a consequence, the participants were frequently housebound and challenged by boredom.

Compounding this isolation was the tendency of all but one participant (Margaret – who still shopped for her own groceries and attended Sunday Mass) to actively avoid social interactions. For example, while two had supportive partners, they did not socialise outside of this dyad; the other participants lived on their own. It seems that even if participants were socially-inclined prior to their illness, once they had commenced PD friends either gradually avoided them, they avoided their friends, or both [Author Query/Revision Request: did both of these happen with the same frequency?]. In this respect Joseph described how while he would have enjoyed meeting people, he couldn't risk offending others by his refusal of "normal things" like tea or coffee. He doubted that people would understand why he could not drink these, nor why he needed to disappear several times a day for extended periods to undertake an exchange of dialysate. Sadly, even when there were adult children or some other family network available, participants noted that family also tended to avoid visiting. As Nancy put it: "they are frightened I might want a kidney", a concern echoed by two other participants. It is also interesting to note that when asked whether they would seek the company of other renal patients if group meetings were an option, every participant was adamant that they would not do so. In this respect, Nancy cited her extreme sense of privacy about her illness, and "anyway, I find them very aloof

and unfriendly”. Terry described other renal patients “as a bit weird ... a funny old bunch”, a typical reaction from all but one participant.

PD is a kidney *replacement* therapy, it is not a kidney, hence it can never substitute entirely for a fully functional organ. This less than perfect function entails some uncomfortable side effects, which were the final challenge to compliance with PD regimen articulated by participants. While health professionals generally make every effort to inform clients of these, there is a wealth of information to absorb prior to managing this procedure at home, and understandably, some of the information is either not heard, forgotten, or missed. It means that once they have made the choice to commence PD, patients may face some considerable and unexpected obstacles. Terry expressed it thus:

Terry: I’m a little miffed ... one of the ladies from the PD department came over and started talking to me about PD before I started ... but since then I’ve found out all sorts of little things that really should have been told to me [then]. And you know, I should have been made aware that there is a chance of a hernia, and your scrotum filling up full of fluid. If I had known that, I would have thought, this is interesting ... And the having a room full of boxes is a problem that she made me aware of to some degree, so that’s pretty fair, but having the machine in the room, it was um, I didn’t expect the alarms to go off as often as they do and keep me awake all night, um that was a problem. ... The thing is, I believe that if I had been given that information at the start then would have walked into PD with my eyes wide open.

Altered cognition is another typical challenge for patients in kidney failure. For example Dan, while obviously functioning well cognitively at the beginning of his morning interview, clearly was not functioning as well towards the end of the

interview and also described several episodes where his thinking was clouded most afternoons. [Author Query/Revision Request: Was this observed by the interviewer?] Whereas most participants had a good general grasp of the purpose of their medications, Dan expressed no desire to learn anything about them, as it was “too hard” and his head “got too fuzzy sometimes”. He also admitted that he often mixed medications up and “when I go to take them I think I ... geez ... I’ve given myself one too many a dose of something”.

Enhancing compliance

The participants had few suggestions as to enhancing compliance with PD. Terry emphasised the importance of husbanding precious energy in order to undertake the necessary procedures:

Terry: Yeah, like I’ve only got so much energy throughout the day, and if I take small sips they are going to last. But if I go gulping at it, it just wears out pretty quickly you know.

Margaret discussed how, even though she was not often able to socialise with others, she would encourage other renal patients in the same situation to seek support from renal organisations such as Kidney Australia. She believed it important to keep up to date with kidney health issues through the newsletters distributed by such organisations and the internet forums they convened. Margaret also described how, when she initially learnt PD, she “did meet a few people in the hospital, and they told me their side of things and how they managed and so forth, that was a great help”. But it is health professionals who appear to be the most significant source of face-to-face socialisation with respect to PD. All of the participants emphasised how they enjoyed

their regular clinical visits, their home visits and the personal interaction with health professionals those visits entailed, and how PD seemed much easier if these people obviously cared. Several participants also related how they always accept invitations to participate in research studies such as this one, because of the opportunity researchers offer to debrief about their treatment concerns and afford personalised discussions about it.

Interpretation

All of these themes are drawn together in the understanding that PD compliance for the participants is a function of maintaining a relatively normal state of being. These data emphasise how *normal* it is for the participants to strive for health by undertaking PD; of how right it is to try to overcome illness-related limitations; of how they wish not to be identified as patients on PD when they socialise, but to look and behave like other people and not feel compelled to withdraw from others or to be isolated from them[Author Query/Revision Request: Reviewers note that this statement appears in conflict with the data about no going out and not socializing and suggest rewording.]; and of how normal it is to conform to the authority embedded in the health professions, particularly when conforming helps to maintain a preferred way of being. The study participants did not question the intrinsic value of PD practices in helping them ensure these things. What they did question was when the recommended PD practices threatened their perceived normality; when procedures marked them as out of the ordinary and too obviously a PD patient. It was only in these circumstances that deliberate non-compliance was evident.

The data also emphasise that given these considerations, ‘compliance’ may be too mutable a concept in this context to enable the development of a concrete definition. For example, all of these patients affirmed that while most aspects of PD as taught should be adhered to in principle, they can be tweaked in practice if such refinements enhance their sense of being normal. Indeed, these participants demonstrated that strict adherence to many of the PD procedures and objective assessments dear to renal nurses – such as daily weights and blood pressure readings, or rote adherence to sterile techniques – is often not necessary. They can be refined or discarded completely with no adverse outcomes, despite them being replaced with those that are subjective, patient-oriented and patient-initiated. This does not mean that patients haven’t complied with health professional advice; it merely means they’ve complied in their own, equally valid way and with reference to their lifestyle considerations. In kidney disease, as in many other chronic diseases, patients are quite capable of monitoring and evaluating their own behaviour. These data made very clear that they are also acutely aware that health professionals are monitoring these behaviours too, and forming judgements about them without really understanding the constraints to compliance that patients experience. Neither do health professionals appreciate the variations of compliance that are often necessary to make patients’ lives easier, but which don’t automatically threaten their health.

The study has sought to recognise and valorise the voice of the renal patient in relation to PD compliance. The issue that resonated most from these patient data is that compliance for patients on PD entails a significant element of normality – of having control over their lives and, within certain parameters, having the freedom to live as they see fit. Given the inherent differences in people, how they must live and

what they consider normal for them, it is reasonable to argue that compliance should not be a narrow concept – it is probably not even truly definable - and the interventions derived from the concept should not force people into circumscribed actions that are dissonant with their life contexts and what they wish to achieve from their treatment. For those patients who are deemed compliant, PD compliance may in fact be the deliberate uptake of biomedical practices that allows them a degree of latitude and a sense of control over their situation. We as health professionals need to be aware of the subjective judgements implicit in our objective assessments of patients on PD, and our compliance strategies should be as fluid and adaptable as the people and contexts with which PD is associated.

The limitation of this study is its small sample of patients who consider they perform PD within the parameters recommended by their health professionals. This prohibits the generalising of the findings to the PD population in general and to those often difficult to access patients who are categorised as ‘non-compliant’. It has, however, given us a feel for what compliance with PD might be from the perspective of this particular group and provided ideas to propel research into PD compliance further. We concurrently investigated PD compliance from the perspective of patients who are considered non-compliant (McCarthy & Martin-McDonald, 2007) and subsequently of renal nurses (McCarthy, et al., 2009). These studies unearthed quite a different notion of compliance and clearly demonstrate the dissonance between patients’ and clinicians’ perspectives of compliance. In further investigations, we would like to revisit the notion of compliance completely, taking it right back to basics in light of these data with a rigorous concept analysis that embraces all perspectives.

Conclusion

The purpose of this study was to come to understand compliance from the perspective of selected renal patients. The foregoing analysis indicates, however, that it may in fact be the actions of health professionals, acting in alignment with individual patient needs and wishes, and demonstrating an awareness of the constraints under which patients operate and the strengths that they bring to their treatment, which may be the most significant issues to consider with respect to definitions of PD compliance. It also seemed to be those behaviours that recognised and best promoted relative normality that were important to the participants in this study, and which informed those activities that demonstrated their concordance with health professionals' advice.

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