

## **Compliance in peritoneal dialysis: A qualitative study of renal nurses**

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### **Abstract**

Endstage renal failure is a life-threatening condition, often treated with home-based peritoneal dialysis (PD). PD is a demanding regimen, and the patients who practise it must make numerous lifestyle changes and learn complicated biomedical techniques. In our experience, the renal nurses who provide most PD education frequently express concerns that patient compliance with their teaching is poor. These concerns are mirrored in the renal literature.

It has been argued that the perceived failure of health professionals to improve compliance rates with PD regimens is because 'compliance' itself has never been adequately conceptualised or defined; thus it is difficult to operationalise and quantify. This paper examines how a group of Australian renal nurses construct patient compliance with PD therapy. These empirical data illuminate how PD compliance operates in one practice setting; how it is characterised by multiple and often competing energies; and how ultimately, it may be pointless to try to tame 'compliance' through rigid definitions and measurement, or to rigidly enforce it in PD patients. The energies involved are too fractious and might be better spent, as many of the more experienced nurses in this study argue, in augmenting the energies that do work well together to improve patient outcomes.

## **Introduction**

A key element of contemporary nursing practice is the preparation of chronically ill patients to manage their long-term health care needs in their home environments. Individuals with end-stage renal failure who practise peritoneal dialysis (PD) are typical of such patients: their damaged kidneys can no longer efficiently perform the vital functions of filtering the blood and removing excess water, salt and metabolic waste products from the body. The procedure of peritoneal dialysis seeks to restore the body's fluid and electrolyte balance by artificially removing such materials. PD patients are taught to self-manage this intricate dialysis technique at home through a permanently implanted abdominal catheter, away from the direct supervision of health professionals, but consistent with the scientific principles that health professionals try to teach them. The procedure is complemented by the patient's monitoring and control of their fluid and nutritional intake, and of many significant modifications to lifestyle.

In some cases, compliance with PD regimen is important because it is not intended to be a life-long treatment. Dialysis cannot replicate the efficiency of a well-functioning kidney, and patients on dialysis never return to their pre-morbid levels of health and function. Where the patient's situation warrants, dialysis is used to sustain life and relative health only until a kidney transplant becomes available. Donor kidneys are comparatively scarce in Australia, and the long-term viability of such a precious resource is considered by health professionals to be completely dependent on the individual's ability to strictly follow medical advice. Patients must therefore demonstrate their ability to comply with a prescribed regimen such as PD prior to receiving a transplant. They must also be relatively healthy to receive a transplant which, in the absence of renal function, is only considered possible with exemplary attention to PD. In other situations, kidney transplant is not a viable option and the patient is dependent for the remainder of their life on PD. When this is the case, avoiding

the many complications of PD (such as local and systemic infection, peritonitis, fluid overload, heart disease, hypertension, hyperglycaemia and death) by observing biomedical principles, is considered by clinicians to be a patient imperative.

Renal nurses regularly confront the poor outcomes that result if the recommended biomedical procedures are not adhered to by PD patients at home. As a result, they direct a great deal of effort towards educating patients about the biomedical and lifestyle practices necessary to ensure the best health outcomes. Hence patient compliance with that advice, which is variously referred to as patient adherence, concomittance or concordance, is a central concern of nurses who work with PD. As many who work in health care have found, however, nothing associated with patient compliance is simple, and failure to comply is considered reasonably common (1).

The apparent incapacity of health professionals to improve compliance rates with regimens such as PD is considered to be rooted in four shortcomings in research and clinical approaches to date. First, compliance has always been difficult to conceptualise and define, and what counts as compliance in one context may not be acknowledged in another (2-4). Second, because we don't know exactly what compliance is, it is challenging to operationalise, quantify and evaluate it in a standardised way in research or practice (5, 6). These two problems mean that PD patients have been reported as failing to comply with recommended PD procedures anywhere between 2% and 100% of the time (Leggat 2005). Third, compliance at present is predicated upon the subjective standards and desires of the health care professional, but what is detrimental from their perspective, and what is detrimental from the patient's perspective, may differ (4, 7). Finally, patients and health professionals appear to have little understanding of each other's perspectives with respect to PD compliance; hence they do not seem to partner very effectively to achieve those mutual

treatment goals that are believed to enhance ownership of health interventions and health outcomes (Richard, 2006: 392; Kutner 2001).

In this study we sought to take the notion of compliance back to basics. Given the mutability of the concept across practice environments, we believe that it is important to thoroughly understand what compliance is in the specific context in which it is expected to operate and in which we professionally interact. In this paper, we report the perspectives of PD nurses, with whom we have explored the meaning of the term for them; the factors that they believe enhance or confound compliance; and how they believe PD patients and nurses can work together to enhance renal health outcomes. A separate study examining PD patient perspectives is reported elsewhere (8). While this paper examines compliance from a nursing perspective, it differs from existing studies in its focus upon localised, subjective constructions of compliance rather than the design and application of generalised measures to define, deal with, monitor and alter patient compliance. It is our belief that only from such precise and contextualised understandings can concepts such as compliance can be usefully developed for research, made measureable and ultimately implemented and evaluated in specific practice settings.

## **Method**

This study was guided by the phenomenological assumptions of van Manen. In this approach, the investigator must first come to understand the phenomenon as it is lived by participants, rather than as it is conceptualised by the researcher (9, 10). Hence, every attempt was made in the data collection phase to bracket the investigators' *a priori* clinical understanding of compliance with PD, and to reflect only on the essential features of this phenomenon that arose directly from the participants' words. For example, while the team member who conducted the interviews was extremely experienced in interview technique

and in health care, she had no theoretical or practical experience in PD. Consequently, she had no preconceived notions of what PD patients should or should not do, or the practice issues related to this treatment modality. As suggested by van Manen, the phenomenon of PD compliance arising in these data was then thoroughly described and thematised through an intensive period of writing, rewriting and team interaction for 18 months. The investigators only came to truly understand the individual nurses' perspectives of PD compliance, however, by recognising that all such phenomena exist in context (9). In accordance with van Manen's method, this meant subsequently placing the themes that arose from our thorough immersion in the interview data firmly amongst the organisational practice context in which they arose, and also locating the experiential descriptions of the participants back within the PD compliance literature (10). In effect, this process considers all of the parts against the whole to arrive at a comprehensive understanding of PD compliance as it operates in a specific milieu (11, 12). The stem questions that guided the collection of the nurse data in this study were threefold:

1. How do renal nurses understand the term 'PD compliance'?
2. What do nurses believe influences PD clients to follow, disregard or refine their advice?
3. How do renal nurses believe they can enhance PD patients' compliance?

Nurse-participants were recruited by purposive sampling, as there was a small maximum pool of ten participants working exclusively in PD in the public health district in Australia under investigation. A total of eight of these nurses participated in the study, with the remaining two on extended leave. All but two nurse participants worked fulltime in PD, with their years of specialised experience ranging from 18 months to 20 years. All were employed in the three government-funded renal facilities that serviced the health district. The combined patient base of these facilities was approximately 400 PD patients from a variety of locations, ranging from remote Australian Aboriginal communities to inner city suburbs.

After ethical approval from the university and three hospitals was obtained, individual audiotaped interviews were undertaken. Taking between one and two hours, these were conducted by an interviewer not known to the participants. Interviews were semi-structured, which facilitated the indepth exploration of personal and professional insights into PD practice. All participants were assigned pseudonyms to protect their privacy.

### **Understandings of compliance**

The nurse participants assumed two different positions when asked for their understanding of patient compliance with PD. The first group, who tended to be less experienced (that is, less than two years' fulltime contact with PD patients) depicted compliance in terms of 'nurse knows best'. They emphasised their own significant role in the performance of PD, even when the procedure was undertaken away from their direct supervision in the client's home. Rachel's view of compliance, for example, highlighted that patient recognition of the nurse's authority is fundamental to her own professional performance, and of her ability to work harmoniously with patients:

Rachel: [Compliance is] doing as they're told. In a nutshell, yeah, that's all. Doing what they're told. To me that's where I get my job satisfaction from. If they're doing the right thing by me, not causing arguments, there's no friction between professional and patient. ... I feel a great sense of satisfaction that I've done my job well and that they're improving. So if they're compliant, that's extremely important. ... When I say 'good clients' I mean the compliant ones. ... They do it without argument and they appreciate the effort that as nurses we put in.

In contrast, nurses with more experience with PD were sensitised to the demands rigid PD compliance places on the patients expected to practise it. These nurses were conscious of how difficult it is for individuals to adhere to a prescribed regimen without due consideration of their personal needs, lifestyle, and individual goals for care. This second group were exquisitely aware of the nuances of power and control embedded in notions of compliance, and how a nurses' assumption of the controlling role might adversely affect patient compliance. They expressed a decided preference for working *with* the patient to formulate patient-driven goals for self-management rather than imposing clinician-derived goals for compliance. So while these experienced nurses understood the importance of the nurse in helping patients practise PD safely, they did not necessarily conceive of themselves as central to the patient's performance of it. Rather, they highlighted the importance of negotiating PD regimens with the patient, and how mutual co-operation may ultimately facilitate successful PD. For example:

Julie: Compliance? Good? We tend to put them together don't we? That is what we [nurses] want. But it's not necessarily what the patient wants. ... You know, this is not an easy thing for people to incorporate into their lives ... it's very difficult, very hard. ... I don't really like the term compliance because I think that it is a militant term. Militancy used by health professionals. ... Compliance is because *we* say they have to do it.

These competing notions of compliance support the contention in recent literature that it is an equivocal and misunderstood concept (1). As Amanda, another experienced clinician, noted: "To be honest I hate the word compliance. It always generates the concept that you can be non-compliant". It seems that for many in health care, compliance can only be understood through the lens of its opposite (non-compliance). Furthermore, even though

compliance is so widely misconstrued by those charged with instilling it, clinicians nonetheless persist in attempting to measure and evaluate it. A myriad of parameters are used to try to quantify compliance. These range from recordings of blood pressure; creatinine production; biochemical markers; weight; fluid and nutritional intake; demographic profiles; use of PD machines; expenditure on PD supplies; visual observation of patient activity; evaluating patient behaviour; and so on (1, 13-17). Yet this fundamental confusion about the real outcomes of compliance can place patients in an unenviable position – they are damned if they do and they are damned if they don't. As Kerry argued, it is apparent that patients may be incorrectly labelled as non-compliant 'bad' patients even though technically they have been 'good', correctly following all biomedical teachings:

Kerry: Patients are often put in a paradoxical position because they can be doing all the right things but still have 'abnormal' parameters and nurses make them feel guilty about this. So that sort of makes them feel 'I'm not doing anything wrong, I'm doing what you wanted me to do, but because you see the fluid or weight gain you think I'm not' ... But there's other factors, maybe they're gaining because it's muscle mass not fluid, maybe they're getting healthier, they're feeling great because they're getting dialysis, so you've got to step back and not blurt out ... 'oh you've gained four litres, what are you doing wrong?'

### **Enhancing compliance**

The nurses in this study perceived the factors that enhanced patient compliance as falling into two broad categories. These were factors arising from the patient's own needs and desires; and factors arising from pressures within their social network. The first category meant the patient was compliant so that they could undertake PD with minimal disruption to

lifestyle and maximum wellness, or so that they could focus on an eventual future without PD. As Julie and Jillian noted, such patient-driven behaviours are important because it is only those patients deemed compliant on dialysis who are eligible for a kidney transplant, which eliminates the need for dialysis altogether:

Jillian: Some embrace their dialysis and they won't let it beat them. They're very, very motivated, they're still working, all that kind of stuff. Those people tend to do very, very well. They get in, they get on with it, they do it. .... Most of the young ones that are still working and stuff, they go on the transplant list so they're very, very motivated to be compliant because one of the issues with transplant is compliance.

Other PD patients were seen as compliant because they subordinated their own desires to those of others. Often, these were family members who "forced them not to die" [Julie] or who were vigilant on behalf of the health care team in ensuring PD compliance. The participants were aware that while co-opting others from the patient's social network could enforce compliance; this strategy does not come without risk. From several instances related by the renal nurses, when these props are removed, compliance can be compromised with disastrous results. Amanda told the story of a patient who, as a prisoner, strictly adhered to the PD regimen, and whose health outcomes had resultantly been excellent. This was only achieved, however, because his prison guards - the compliance 'enforcers' - ensured he followed his treatments. When he was released from their supervision, he nearly died:

Amanda: ... [After he was released from prison] he thought he felt fantastic and he turned up to our clinic ten days later. I think he was twelve kilos over with fluid and

overloaded with potassium which was not supporting life. And he said “Well, I felt fantastic, I didn’t see why I couldn’t go off and see my family” ... a very reasonable thing to say, he just felt fine, therefore he thought he *was* fine. Hmmmm. He wasn’t too fine when he back to us though ....

### **Factors influencing compliance**

The previous section illustrated that patient compliance with PD procedures may be the result of personal motivations or a response to the pressure of others within the patient’s social network. The data also made it apparent that compliance may be influenced by several other factors. These include the patient’s inability or their deliberate choice not to participate in PD, or the ‘sabotage’ of their intention to comply. For example, apparent non-compliance often resulted from malfunctions in the PD equipment. As many of the participants also noted, patient non-compliance may also be a direct result of the physiological processes inherent in renal failure itself:

Julie: But what is normal? I am trying to teach someone who by definition has a chronic illness [ie who is not normal]. So we can’t apply principles like we would in an ordinary environment to these people who by definition are sick. They’ve got other problems related to their illness ... maybe these patients aren’t non-compliant, but maybe it’s because they can’t remember or they haven’t taken it in properly and it’s only been said once to them. ... I think we need to see them as having the complications associated with renal failure, e.g. short term memory problems, and that’s where compliance comes in because did they actually remember? Did they actually learn?

Julie is referring here to the high blood urea and creatinine levels that characterise renal failure even if dialysis occurs regularly, which can impair the patient's cognitive abilities and engender extreme fatigue. These symptoms make it difficult for some renal patients to absorb the detailed teaching required, and limit their energy to do things the way they have been taught. So we need to consider whether such physiological markers interfere with the patient's intent or ability to comply. This places an imperative on the health professional to ensure communication occurs in a format that the patient comprehends and is capable of mobilising.

It is also worth bearing in mind that an apparent instance of non-compliance can be used as the catalyst for patient compliance. A story from Jillian illustrates this well:

Jillian: It takes an event, and I'm thinking of one patient, but it took her to have a respiratory arrest to realise that she was drinking too much. She had like 20 litres ...of fluid gained and she found it really, really hard to breathe. They were trying greater strength solutions to get the fluid off, and the dietician ended up being called back in to give the education on fluid restricting. ... We found out later, the dietician got out of her, that her "cups" of tea were actually mugs. So instead of having like 250ml she was having 500ml at a time. So sometimes it takes an event for them to realise okay, I have been doing the wrong thing, I've had blinkers on, and they finally start listening.

What is striking in this exemplar is that the focus is not placed on health professional failure to teach the patient properly, but on the patient's "blinkered" approach to her own education. Nonetheless, such dramatic health events can also force the health team realise

the need for an evaluation of their teaching approach and how they communicate essential messages to patients.

It is clear that social networks can be recruited into compliance activities. Paradoxically, compliance can also alienate PD patients from those very networks, resulting in non-compliance. Some of the nurses discussed how the PD regimen demands lifestyle alterations of the patient that they find undesirable or unmanageable, and which marginalise them from their social networks if they follow PD teachings exactly as taught. For example, PD patients must have scrupulously clean houses with rooms set aside for numerous bulky PD supplies. They are often advised to discourage visits from very young children, who may inadvertently dislodge their abdominal catheter if they become very active during close contact. These restrictions can be off-putting for potential visitors, who do not wish to compromise patient sterility and safety, or “invade an already invaded space” [Brenda]. Additionally, many renal nurses noted non-compliance can arise when the socio-cultural networks supporting patients are damaged or ignored. A patient from a culture that prioritises the concerns of significant others over self, for example, may appear non-compliant. Yet it is important to understand that other personal commitments or the needs of others might preclude them from attending every clinic visit; catering to their own specific dietary requirements; or from spending precious finances on their own medications rather than other demanding and necessary expenses. Amanda pointed out that a lack of cultural exposure to Western biomedicine is particularly important in the practice context investigated here. She noted the difficulties some Indigenous Australians (who comprise a disproportionate number of renal patients in this setting) have with absorbing renal education and biomedical techniques and norms if they had experienced limited previous contact with the Western health care system.

### **Finding the middle way: working with PD patients**

The participants have illustrated that in this practice environment, generic clinical definitions of PD compliance in which to ground subsequent measurements and evaluations might not matter to patient outcomes. What does seem to matter is the goal of renal health, the individual needs of those who are focused on that goal, the context in which they are operating, and how that goal might be attained within the constraints of that context. The foregoing discussion has illustrated that this might be achieved by first understanding how those involved with PD can facilitate or inhibit PD regimens at present. This was explored in the first part of this paper. The second part of the paper will examine how that understanding can be directed towards the goal of compliance.

Here, it is worth considering the possibility of definitional fluidity. As revealed in the renal literature and as explored here, unbending approaches to compliance foster brittleness, and a propensity to fracture when tensions inevitably arise. Paradoxically, PD procedures and the potential for patient success may be more robust if biomedical approaches to PD are more fluid. Fluidity does not mean that PD processes and procedures mutate into a free-for-all procedure where patients and nurses can do as they please. Safe practice requires some boundaries. What defines these boundaries and subsequently structures PD activities is the consistent focus of the individuals involved on a specific goal: renal well-being for patients undertaking PD. The experienced nurses in this study noted that this goal does not necessarily have to be mediated through 'compliance' as determined by the health professional. Furthermore, working towards fluidity does not mean that adaptations to PD procedures should be introduced all at once, for such pressures may place unbearable tensions on PD and the patient. It also ignores how the existing processes may work well for some patients. We suggest that one practical strategy might be to whittle away at the novice nephrology nurse's consciousness of compliance, demonstrating that apparent failure to

comply is not necessarily a negative trait of the patient. Health professionals might cultivate sensitivity to the ways that patients must come to terms with the frequently fractious PD processes that are usually not of their own choosing.

Flexibility is also required in determining how safe and healthy PD practice is achieved. All of the participants gave examples demonstrating that PD patients often instigate a streamlining process as they become familiar with the procedure, with or without nursing approval. They learn to iron out little kinks and develop shortcuts that often do them no harm and coincidentally, confer upon them a greater sense of control over their situation. Patients evolve their performance of PD in order to make it function for them, their lifestyle and needs; moulding the regimen but 'compliant' enough to ensure their health and safety. The practices of health professionals can change over time too, with a flow-on effect to the PD patient and to the ultimate configuration of PD. As Brenda so elegantly expressed it in the following analogy, it is all about making PD safer, more reasonable and practical for everyone involved in it:

Brenda: Think of all those beautiful old early cars. But they had all these sticking out knobs and hard surfaces and that sort of thing. And so when people had an impact in them, those things would sort of penetrate people if the car crashed. So the Volvo and Mercedes manufacturers way back then thought, oh well, accidents happen so how do we make the result safer? And so that's when they started to gradually streamline the dashboard and then of course it's now up into crumple systems. [So PD should be about] how can we make it safer? How do we sort out the alternatives that we have to put in place as a sort of backup? And I think that's how we as health care providers have to deal with compliance.

These data illustrate that attempts to enforce a clinician-determined model of PD compliance do fail. At the same time, there is a need to ensure the patient gains optimum benefit and minimum harm in their practise of PD. By integrating a degree of flexibility into PD with respect to the needs of the patient, the nurse and the PD regimen itself, a mutually satisfying outcome can be reached. Thus, terms such as compliance and non-compliance are useless, as mutual negotiation is key to PD success. So what might the fluid, negotiated PD process look like?

Amanda: In a perfect world the recommendations from the health care professionals would have been done in conjunction with the patient. And there would be a full understanding between the health care professional and the person receiving care to have a plan of care that would meet both their needs in the best possible way. Then there would be no issue of compliance ... because your plan is your patient's plan, informed by good education. And it has to be flexible and has to evolve as the person's situation changes. ... It goes back to quality again and prioritising what is most important for the patient at the time. Whoever's life it happens to be.

## **Conclusion**

This discussion has explored compliance with PD regimen from the perspective of PD nurses practising in a defined context. It is very clear from these data that no individual PD action in this context occurs in isolation, and each action has an impact on PD outcomes. PD and PD 'compliance' cannot happen without these many interconnected parts; hence PD compliance cannot be pinned down to the one individual patient charged with carrying it out or the health professional who thinks they can instil it. Perhaps health professionals need to reframe their thinking, particularly in terms of their perceived role. These nurses have

identified that sometimes, patients cannot comply due to the interference of personal, social and technical issues. At other times, the patient's situation is such that they genuinely do not see the need to. Yet for other patients, the various influences on PD do not interfere with their practise of the regimen as taught. Patients are the focal point of PD, to whom all energies are directed. Perhaps we can make more effort to understand the environment in which we expect them to practise regimen; the constraints on their hoped-for behaviour, and the things that might help them achieve the well-being that their renal health team are also working towards. Then we can understand how to help them achieve their renal health goals with more realistic expectations on all sides.

This brings us to the notion that irrespective of biomedical efforts to stabilise and sustain PD patient 'compliance', long-term sameness and universality in compliance is neither possible nor desirable in this practice environment. While certain PD processes always need to happen to keep PD viable, it is neither pragmatic nor reasonable to expect them to happen in the same way every time and in every context. There needs to be freedom to evolve, for changes and modifications will happen irrespective of whether freedom is sanctioned or not. In fact, the more adaptable the elements of PD are, the more fluid and adaptable PD becomes. It is the rigidity of 'PD compliance' as currently conceived that makes it prone to breakdown and fracture, thereby compromising PD. In effect, the data in this study illustrate that it may be pointless to try to tame the elusive concept of compliance through rigid definitions and measurement, or to try to rigidly enforce it in PD patients. The energies involved are too fractious and might be better spent, as many of the more experienced nurses in this study argue, in augmenting the energies that do work well together to improve patient outcomes.

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