

Patient Centred Renal Care – Psychosocial Care for Patients with Renal Disease

Author: Michael Kelly. EDTNA/ERCA Psychological Care Consultant, Ireland | mike@ika.ie

Learning Outcomes

- Be conscious that psychological distress is prevalent in patients when diagnosed with or on treatment for kidney disease.
- Be aware that this psychological distress will manifest itself in patients attitudes and behaviour.
- Remember that patients behaviour may be a communication of their psychological distress and if so, it is this that needs to be addressed, not their behaviour.
- Always keep in mind the sense of powerlessness patients feel and how this will find expression in their relationship with nurses and allied health professionals.
- There are tools to help nurses and allied health professionals support patients and help ease the sense of powerlessness they feel.

Introduction

With the development of the dialysis machine the possibility of life saving treatment became a reality. Yet from the very beginning, while the physical needs of patients could be met through dialysis, there was a growing recognition that dialysis treatment brought with it psychological trauma. This psychological trauma finds expression in many different ways, for example, aggression and anger, depression, fear, non-adherence to diet and medication. It is often the nurse or allied health professional who has to contain the psychological trauma their patients experience. This they do in a variety of ways, sensitivity to patient needs, listening and understanding and giving time. Yet are there other areas that can be overlooked, not because they are missed but perhaps because they are too obvious. In this article some of these areas will be illustrated and explored enabling a deeper understanding of the significant impact they have on our patients and on their accommodation to treatment regimes. The hope is that this will lead to a deeper understanding and awareness of what our patients experience and will result in a more holistic approach to their care.

History

Cameron¹ in his book reviewing the history of the development of dialysis treatment from the 1950's onwards said 'we cannot list the physical problems that early patients on

long-term dialysis suffered without briefly remembering the psychological problems that they faced as well. Cameron goes on to say that 'the combination of relief at being alive, altered body image, change in lifestyle, dependence and loss of autonomy, anger, frustration, fear of the future, of connecting to the machine – and of the machine itself, with no clear idea of what would happen next – was a potent mix of problems, many of which still remain to confront patients today' He concludes by saying 'the psychological damage this could bring was evident very early'.

Shea et al² published a study in 1965, in which they concluded that 'from the subjective view of the patient, the emotional reaction to the need for chronic dialysis may represent the greatest obstacle to successful rehabilitation'

In an article published in 1968 in the British Medical Journal, Cramond et al³, paints a very vivid picture of the psychological component of a diagnosis of and treatment for chronic kidney failure (CKF). The paper concludes by saying that 'we must never lose sight of the complex emotional and social needs of the patient and their family'. The paper underlines the importance of staff understanding the patients pattern of handling fear and anger 'since both emotions.....will be aroused'

The following year, 1969, a study by Abram⁴ concluded that dialysis patients 'think of themselves as not entirely human and therefore "freakish"

In her seminal study in 1974, Kaplan de Nour⁵ said that many patients 'on dialysis come to perceive themselves as part of the machine or to endow the machine with human qualities'

Ten years later, in 1984, a study by Nichols and Springford⁶ focused on the prevalence of denial as a coping mechanism used by patients on haemodialysis which further underlined the 'psychosocial problems associated with survival by haemodialysis'. The results of a study by Petrie⁷ in 1989 found that 43% of dialysis patients suffered some level of psychological disturbance.

A study conducted by Wolcott et al⁸ and published in 1988 'suggested that 20-30% of dialysis patients have clinically significant affective disorders'.

Murray Parkes⁹ has written extensively about psychological care related to physical illness. While not specifically referring

to dialysis patients, he underlines the importance of acknowledging the psychological element by urging those working with patients, in whatever capacity, to 'cultivate sensitivity to the possible psychological influences of the physical illnesses that come our way'.

Historically we can say that since the introduction of the treatment of chronic kidney disease by dialysis, it was recognised that the psychological element played a significant part in how the patient viewed their treatment, viewed themselves, how they imagine they are viewed by others, how they adapted or failed to adapt to their treatment regime. What is also clear from the historical evidence is that failure to address the psychological concerns of patients and their families is detrimental to their and their family's well-being.

Our Awareness

Of course as nurses or allied health professionals we are aware of all this. This history is lived out on a daily basis in our dialysis population. We know that our patients (and their families) suffer both emotional and psychological distress when diagnosed and when treatment begins.

We know that the treatment pathway is not smooth and that there are moments and times of increased emotional stress and fragility, particularly when problems arise, for example, if a fistula does not work or the PD line becomes blocked, or when the patient has to attend hospital for a procedure.

We know that many of our patients feel angry, frustrated, uncertain, fearful, concerned about the future and a myriad of other emotions.

We know that our patients grieve for the person they once were, for the body they used to have, for the things they once could do, for, perhaps, the job or career they once had, for the companionship they enjoyed and for the hopes and dreams that can no longer be realised.

We know that our patients suffer from fatigue, decreased energy, impaired concentration, insomnia, weight loss and restricted use of the extremity with the creation of the fistula and that this contributes to the levels of stress they experience.

We know that being ill makes people feel vulnerable. Some patients deal with this anxiety by becoming angry, others react by being 'good' patients, out of fear that if they misbehave it will have an impact on their treatment.

We know that, as McClintock Greenberg¹⁰ states: 'adjusting to illness requires patients to accept loss, manage the blow to the ego that illness causes and cope with anxiety and manage feeling more dependent'.

Dr Duncan Thomas, who wrote two very informative, interesting and well worth reading articles in the Journal Of Renal Care¹¹ (JORC), gives us a very open and honest account of the impact his diagnosis and treatment had on him. He says 'living with chronic kidney failure requires a significant amount of will-power and determination to continue normal daily activities'. He goes on to describe fatigue as 'an ever increasing monster with which to battle daily'. All of this he concluded produces

'an emotional fragility which necessitates a significant level of understanding from family, friends and loved ones' and this applies to staff as well.

Powerlessness - an unseen but ever present feeling

McClintock Greenberg¹² writing about those diagnosed with severe illness says that patients 'are often taxed with the impact of bodily changes and decline, physical pain, and fear of death: surviving from day to day involves tremendous physical energy and as a result, psychological energy that might be employed to address emotional issues is reduced'. This is true of our patients. The demands of ongoing treatment, fatigue, restrictions on diet and fluid all contribute to the patients' difficulty in focusing on the ever present emotional issues present.

From this we can say that a diagnosis of and treatment for chronic kidney disease provokes a significant emotional reaction in people. Two of the reasons for this are that in life all of us carry certain assumptions, one of which is that we expect to be healthy most, if not all of our life. With a diagnosis of chronic kidney disease this assumption is shattered. A second assumption we have is in relation to illness. Illness is often thought of in acute terms, in other words, diagnosis, medication and cure. With a diagnosis of a chronic condition this mind set is challenged. With a chronic condition our patients have to face the unpleasant reality that while there is treatment there is no cure. It is life changing and lifelong diagnosis.

This is not something that is foreign to us. It is familiar. We see it in our patients daily. However one issue - with its many manifestations - that can get overlooked is the sense of powerlessness our patients feel. This growing sense of powerlessness will find expression often in their attitudes and behaviour, for example, through anger, aggression, and frustration, silence, missing dialysis sessions and not adhering to diet or fluid allowances. Powerlessness disables in a subtle and powerful way.

What contributes to our patients' sense of powerlessness? And what can we do to decrease the powerlessness our patients feel? There are a number of factors, some which can be easily overlooked, identified in studies and from my experience of working with patients that contribute to powerlessness.

Environment

As nurses or allied health professionals our place of work - the hospital - is familiar to us. We know its geography, the layout of the hospital, the signage. We know where the canteen is, the coffee shop, the location of the clinic rooms and the toilets. We know our way to and from the wards. We can find our way around with ease. It is, in the words of McClintock Greenberg¹², the place where 'people talk fast, move fast and think fast'.

Not so for our patients, particularly in the early stages of treatment. For the person becoming a patient the reality is quite different. For us, our place of work, the hospital environment is familiar, with its own structure, culture and routine. However

for the person new to the hospital it is an environment that is, in the words of one patient, 'alien', with a structure, culture and routine unfamiliar to them. Our natural reaction when we are in a place that is unfamiliar or unknown is to feel anxious. This is what our patients experience particularly in the early days of diagnosis and treatment. Psychologically they feel vulnerable with a growing sense of powerlessness. As McClintock Greenberg¹³ writes; people who have to attend hospital are 'suddenly immersed into the medical world, something most people are unprepared for'.

Furthermore we must not lose sight of what hospital 'means' to our patients. For some it may be associated with death, perhaps the death of someone close. It may be associated with previous surgery or be recalled as a negative rather than a positive experience. Hospital is not a place where people want to be but because of their diagnosis, they have to be. This contributes to their sense of losing control of their lives and of feeling powerless.

Time

Another factor within this environment that contributes to our patients' sense of powerlessness is time.

A study of haemodialysis patients by Moran¹⁴ et al (2009) concluded that 'the participants indicated that they spent a lot of time waiting when they attended haemodialysis therapy'. For those of you reading this who work in a haemodialysis unit, you will be aware of this. The daily routine of a haemodialysis unit, putting people on, taking people off, daily routine is very familiar to you. You also know the order in which patients are put on contributes to the smooth running of the unit. Yet those patients who are waiting in the waiting room are sensitive to the order people are put on and this can cause friction, tension and occasionally arguments either between staff and patients or between patients themselves.

I recall, while working in a hospital in London, patients who had travelled for hours to get to dialysis feeling quite put out if someone who had not travelled as far was put on before them. Often the reason the order is as it is is clear to staff. However if this is not explained to the patients - and I would add explained frequently - it can lead to misunderstanding, and once again, from the patient perspective, confirm in them how powerless they feel.

Unexplained delays, long waiting times whether it is at clinics, in dialysis units or in other hospital departments patients are referred to, without adequate communication, contributes to the patients' vulnerability and powerlessness. As one patient succinctly said; 'going into the hospital is like going into another time zone'.

In addition, the perception of patients', according to the results of Moran's study, is that the time spent waiting is not seen as productive but rather as wasted. Feeling that time is being wasted can lead to a growing sense of resentment and frustration in many patients. How this will or will not be communicated will differ from patient to patient. Some patients will express it verbally or through behaviour which may not be appropriate,

and it is staff that often bear the brunt of this. Other patients will say nothing because as Stapleton¹⁵ states 'survival depends on compliance with the health care system demands'.

Staff/patient relationship

Yet another indicator; is the imbalance in the staff/patient relationship

This of course is obvious. We are the professionals. We are the ones who studied, who qualified; we are the ones with the knowledge. That in itself creates an imbalance which creates a dependency between patients and staff. Feeling dependent raises issues around trust and safety. Feeling dependent is a commonly held concern for patients. From the patient perspective it requires patients to navigate changes in how much they need others to help them. Patients depend on medical personnel. In this they have no choice. They need our expertise. This can be a difficult and demanding, and sometimes a slow transition for patients to make, particularly for those who grew up in an environment where they had to be self-reliant. Feelings of dependency can accentuate their feelings of vulnerability and powerlessness. What also should be kept in mind is if the patient has had a previous negative experience of doctors/nurses or hospital, then their level of trust may be lower and their sense of powerless greater.

What we must also never lose sight of is the fact that we are there, in our place of work, to PROVIDE care and treatment to our patients. They are there, not because they want to be but because they need to be. We provide care and treatment; they are there to RECEIVE care and treatment. This immediately creates an imbalance in the relationship between us and them, emphasising our power and underlining their powerlessness.

Haemodialysis Machine

For patients receiving haemodialysis, the dialysis procedure can contribute to their sense of powerlessness. Once attached to the machine, the patient is rendered immobile and this will last for a number of hours. During this time they cannot meet some of their own needs. They may also experience uncomfortable symptoms (leg cramps, nausea, to name but two) but 'no matter how uncomfortable or inconvenient dialysis is, if the individual wants to live, then he or she is dependent upon a machine'¹⁵.

Signage

A further example is signage. Signs are there for a purpose; to convey information or give direction. Yet some signs, innocent though they may seem, can remind the patient how powerless they are. A patient on haemodialysis said the following; 'prior to each dialysis session I have to be weighed. As I stand on the scales, I am reminded by the sign that you must have your weight verified by a member of staff. At one time, I might have been responsible enough to raise a family, but now I am not responsible enough to weigh myself'. This is a simple sign. It is there to convey a message, yet from this patient's viewpoint, the message it conveys is utterly different to the one intended.

Patient Behaviour

Another indicator of powerlessness can be seen in how patients behave. Many patients for a variety of reasons behave in a passive way. They follow our direction without comment or question. A further indicator of this passivity is the difficulty they may have in making even small decisions when they are given the opportunity to do so. We may describe these patients as 'compliant' but let this not blind us to the underlying feeling their passiveness points to; their feeling of powerlessness. Another manifestation of this is that this group of patients demonstrate a marked failure to seek information about their condition or health.

Allied to this is that many patients who feel powerless, not only fail to seek information but will often fail to share information. On one occasion I recall a nurse telling me that they asked one of their patients to weigh themselves on their dialysis off days. Some days later when the nurse asked for the information the patient informed her that she did not have a weighing scales at home!

What I am emphasising here with these six examples is that the environment, in all its complexity impacts significantly and differently on each one of our patients. Their sense of powerlessness can significantly affect how they view treatment, how they view us as the people assigned to their care and to how they communicate with us.

If we believe in holistic care and this is our aim then we need to be aware of and sensitive to those factors that potentially undermine our capacity to provide this care.

Is there anything we can do to alleviate our patients' sense of powerlessness?

A review conducted by Hudson¹⁶ et al 'identified that elevated distress occurs when individuals believe that they have a lack of personal control over their ESKD and a poor understanding of it', This elevated stress contributes to a patient's sense of powerlessness. Stapleton argues that intervention by nurses can be beneficial in helping alleviate the stress and sense of powerlessness patients feel. One of the aims of this intervention is to encourage patients to take more control. How is this to be done? Stapleton¹⁵ offers some useful pointers including; 'modifying the environment, setting realistic goals, increasing client and family knowledge, enhancing the health team's sensitivity to potential causes of powerlessness and facilitating verbalisations of feelings'

If, as nurses or allied healthcare professionals, we can help our patients identify the factors that contribute to their sense of powerlessness and encourage them to verbalise these feelings then we create a basis for problem solving. From this base patients can be helped to take more control, to become more of a participant, rather than just a recipient, in their care. The more control our patients have the less powerless and dependent they feel.

Helping our patients set realistic goals is another useful tool we can use to help alleviate our patients' sense of powerlessness. These goals have to be realistic and achievable which

means they have to be individualised for each patient. Patients who feel depressed or hopeless may find this more difficult and therefore they will need assistance from staff. While this is a useful tool that can benefit patients and reduce their sense of powerlessness, it is also important to acknowledge that it is time consuming for staff. While it may be worthwhile, it may not be feasible due to time constraints.

Summary

Historically, there is an acceptance that a diagnosis of and treatment for chronic kidney disease causes psychological distress

Patients' sense of powerlessness contributes greatly to the psychological distress they and their family experience

How powerlessness will manifest itself will differ from person to person and from institution to institution but there are some common themes.

Our awareness of how our patients are affected and the actions we take can help reduce the sense of powerlessness our patients feel, thereby reducing their and their family's psychological distress

There are strategies to help us in this task

Good mental health in our patients contributes to good physical health within the limits imposed by their illness.

References

1. Cameron, J.S. 'History of the Treatment of Renal Failure by Dialysis'. Oxford University Press: Oxford; 2002.
2. Shea, E.J, Bogdan, D.F, Freeman, R.B, Schreiner, G.E. 'Haemodialysis for Chronic Renal Failure: IV Psychological Considerations'. *Ann Intern Med.* 1965; 62 (3), 558-563.
3. Cramond, W.A, Knight, P.R., Lawrence, J.R., Higgins, B.A., Court, J.H., MacNamara, F.M., Clarkson, A.R., Miller, C.D. 'Psychological Aspects of the Management of Chronic Renal Failure'. *British Medical Journal.* 1968; 1, 539-543.
4. Abram, H. 'The psychiatrist, the treatment of chronic renal failure and the prolongation of life – Part 2'. In *American Journal of Psychiatry.* 1969; 126:157-167.
5. DeNour, A & Czaczkes, JW. 'Personality and adjustment to chronic haemodialysis'. In N.B Levy (Ed), *Living or dying: Adaptation to haemodialysis (102-1126).* Springfield, Il. 1974
6. Nichols, K.A. & Springford, V. 'Psychosocial difficulties associated with survival by dialysis'. *Behaviour Research and Therapy.* 1984; 22, 563-574
7. Petrie, K. 'Psychological wellbeing and psychiatric disturbance in dialysis and renal transplant patients'. *British Journal of Medical Psychology.* 1989; 62, 91-96
8. Wolcott, D.L. Nissenson, A.R and Landsverk, J. (1988) 'Quality of life in chronic dialysis patients'. In *General Hospital Psychiatry.* 1988; 10,267-77
9. Murray Parkes, C. 'The challenge of physical illness'. In Murray Parkes, C, Markus, A (eds). *Coping with Loss: BMJ Books.* 1998
10. McClintock Greenberg, T. 'The Psychological Impact of Acute and Chronic Illness – A Practical Guide for Primary Care Physicians'. Springer Inc, New York. 2007
11. Thomas, D. 'Riding the emotional rollercoaster renal transplant from a doctor's perspective'. *Journal of Renal Care.* 2010; 36 (3): 145-148
12. McClintock Greenberg, T. 'Psychotherapy with Medically Ill Patients: Hope in the Trenches'. In <http://www.psychotherapy.net/articles/psychotherapy-medically-ill-patients>. 2010
13. McClintock Greenberg, T. 'The Psychological Impact of Acute and Chronic Illness – A Practical Guide for Primary Care Physicians'. Springer Inc, New York. 2007
14. Moran, A, Scott, P.A, and Darbyshire, P. 'Existential boredom: the experience of living on haemodialysis therapy'. In *Med Humanities.* 2009; 35:70-75
15. Stapleton, S. 'Powerlessness in Persons with End-Stage Renal Disease'. In Fitzgerald Miller, J. editor. *Coping with Chronic Illness – Overcoming Powerlessness*, 3rd Edition. F.A. Davis Company, Philadelphia: 2000
16. Hudson J.L., Moss-Morris R., Game D., Carroll A., Chilcot J. 'Improving Distress in Dialysis (iDID): A tailored CBT self-management treatment for patients undergoing dialysis'. *Journal of Renal Care.* 2016; 42 (4), 223-238

