

**Pictures and perspectives: A qualitative descriptive study
of the experience of living with fluid restrictions for
people undertaking haemodialysis in a community
setting**

Submitted for the requirements of a Master of Philosophy (Nursing)

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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository**, subject to the provisions of the Copyright Act 1968.

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Peter Sinclair

List of publications and conference presentations

Publications

1. Sinclair, P.M. & Parker, V. (2009). Pictures and perspectives: A unique reflection on interdialytic weight gain. *Nephrology Nursing Journal*, 36 (6), 589-597.

Conference presentations

1. Sinclair, P.M. Parker, V. & Kable, A. (2010). Pictures and Perspectives: A Unique Reflection on Interdialytic Weight Gain. American Nephrology Nurse's Association Annual Symposium, San Antonio, Texas.
2. Sinclair, P.M., Parker, V., & Kable, A. (2010). A picture tells a thousand words: living life with fluid restrictions. 39th International EDTNA/ERCA Conference, Dublin, Ireland.
3. Sinclair, P.M. & Parker, V. (2008) Interdialytic weight gain: The transition to acceptance. Renal Society of Australasia Conference, Sydney, New South Wales.

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Abstract

“Fighting nature is like fighting yourself, and it takes strength”

People undergoing haemodialysis are required to follow a complex treatment regimen that includes dietary and fluid restrictions. Fluid restrictions are reported to be the most difficult component of self-management for people with end stage kidney disease. Historically, research into interdialytic weight gain, a marker for fluid restriction adherence, has focused on interventions devised by clinicians and utilised quantitative methodologies. There has been little consideration given to how people experience fluid restrictions.

This study set out to understand what it was like for people with end stage kidney disease, who were undergoing haemodialysis, to live with the restriction of fluids and in particular to answer the research question: What is the experience of fluid restriction for people receiving haemodialysis in a community based setting? The study used a qualitative descriptive design, in-depth interviews were conducted to explore the experience of living with fluid restrictions in a group of six women and one man who received haemodialysis. Participants were invited to use artefacts to support their story telling. The study was conducted in a community based dialysis unit in a large regional city in New South Wales, Australia. Data were analysed using an iterative process of comprehending, synthesising, theorising and recontextualisation to identify emergent themes.

Themes identified were magnitude of loss, constant struggle and accepting. Accepting fluid restrictions was not a linear progression to understanding and adherence but a multifaceted, tortuous struggle unique to each participant. Over time participants were able to develop and consolidate coping or management strategies into their lives. In varying degrees, these strategies assisted them with managing their fluid restrictions more effectively, but the reminder that they could no longer drink freely as they once did, was always present. In time, participants described that they had come to terms with accepting fluid restrictions in their lives yet acknowledged that they were fallible and prone to times when the temptation to have an additional drink became too much.

Successful adaptation to fluid restrictions was largely dependent on support, the acknowledgement that their lives were worth living, and the understanding that the outcomes of not following prescribed restrictions had both short and long term physiological consequences. However, accepting fluid restrictions and engaging in surveillance and maintenance behaviours, did not ameliorate the constant struggle or the magnitude of loss that each participant faced.

Overall, participants described the unnaturalness of not being able to drink spontaneously. Consequently, adhering to strict limitations of fluid intake was *“hard, very hard.”* While previous research has identified the effect of end stage kidney disease on peoples’ lives, this study has contributed to a deeper understanding of the inescapable and omnipresent nature and influence of fluid restrictions on these peoples’ lives. This is the first study that has focused on describing the experience of living with fluid restrictions for people receiving haemodialysis

Prologue

I have spent the last few years engaged in this study and writing these chapters. Each day, or night I would sit at my desk with a cup of coffee, or a bottle of water. When I needed a break I would take the dog for a run or go for a ride on my bike to clear my mind. During this time I could drink up to two litres of water. When I returned home I would drink more water to refresh me and restore the fluids I had just used. Some days I spent eight to ten hours writing and reading and would easily drink two to three litres of fluid in that time. I get thirsty, so I drink; I go out with my friends, and I like to have a drink with them. How would I manage if I developed end stage kidney disease and restrictions were imposed that prevented me from drinking when I wanted to, or if I was thirsty?