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)

November, 2012

Peter Sinclair, B Nursing, Renal Certificate
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.

**Unless an Embargo has been approved for a determined period.

____________________
Peter Sinclair
List of publications and conference presentations

Publications


Conference presentations


Acknowledgements

My sincere thanks go to all the people who assisted in the making of this thesis and the successful completion of this research project. In particular, the people with end-stage kidney disease whom have taught me the right and wrong way to speak with them about the challenges they endure away from the dialysis unit. A special thank you goes to the seven men and women who shared their experiences of living with fluid restrictions with me. As I promised to you all, I have told your stories via publication and at conferences so that Health Care Professionals can reflect on the way they speak to people undertaking haemodialysis about issues like fluid restriction.

Thank you to my supervisors Ashley Kable and Vicki Parker. To Ashley for helping me develop my writing style, always being available and for listening first, without having to give advice unless I asked. Your patience and dedication was never unnoticed. To Vicki, thank you for helping me understand the importance of the subjective nature of the patient experience. Your patience and ability to manage my frustrations when I could not see the end of this project will not be forgotten. To you both, thank you for the hours of dedication to teaching me the art of qualitative research, thank you for reading and editing this thesis and thank you for your belief in my ability to succeed.

Thank you to Professor Debra Creedy for reviewing this thesis prior to submission, your encouragement and wisdom has guided me ever since I was a first year nursing student. Thank you for teaching me to write (you may not remember but I do!).

My biggest thank you goes to my wife and children. I know this has not been easy for you all. Kim, thank you for giving me the time and space to work on this project. Your willingness to sacrifice your own professional ambitions so that I could achieve mine is something I will cherish forever. Aiden and Imogen, thank you for keeping quiet while I was writing and thank you for asking me how I was going with my thesis at dinner time. Next time you ask I can say it is finished!

Peter Sinclair
Newcastle
AUSTRALIA
November, 2012
# Table of Contents

List of publications and conference presentations .......................................................... 2
Acknowledgements ........................................................................................................... 3
Abstract .......................................................................................................................... 8
Prologue ......................................................................................................................... 10

**Chapter 1**

Introduction ..................................................................................................................... 11
1.1 A background on chronic kidney disease, end stage kidney disease and renal replacement therapy .......................................................... 13
1.2 Fluid restriction and interdialytic weight gain ......................................................... 14
1.3 Background to this research ..................................................................................... 17
1.4 Structure of this thesis .............................................................................................. 18

**Chapter 2**

Literature review ........................................................................................................... 19
2.1 Background ............................................................................................................. 19
2.2 Search strategy ........................................................................................................ 20
2.3 Summary statement ................................................................................................. 21
2.4 Results ..................................................................................................................... 21
2.4.1 Loss ..................................................................................................................... 21
2.4.2 Restriction .......................................................................................................... 23
2.4.3 Redefining self: a new sense of normalcy .......................................................... 24
2.4.4 Adjustment: Impact of the health care system and health care professionals ................. 28
2.4.5 Adjustment: decision making and control (learning to manage) ......................... 29
2.4.6 Support and coping ............................................................................................ 31
2.5 Discussion of findings ............................................................................................ 32
2.5.1 Future research .................................................................................................. 34
2.6 Justification and purpose for this study .................................................................. 35
2.6.1 Research question .............................................................................................. 36

**Chapter 3**

Research design ............................................................................................................ 37
3.1 Introduction ............................................................................................................. 37
3.1.1 Research question ............................................................................................. 37
3.2 Research design ...................................................................................................... 37
3.3 The research setting ................................................................................................. 40
3.4 Ethical considerations .............................................................................................. 40
3.5 Research processes ................................................................................................ 41
3.5.1 Preparing for recruitment .................................................................................. 41
3.5.2 Inclusion criteria ............................................................................................... 41
3.5.3 Exclusion criteria .............................................................................................. 42
3.5.4 Participant recruitment ...................................................................................... 42
3.5.5 Data collection .................................................................................................. 43
3.5.6 Data analysis ..................................................................................................... 46
3.6 Ensuring the rigour and trustworthiness of the data ............................................. 47
3.6.1 Credibility ........................................................................................................ 49
3.6.2 Dependability .................................................................................................. 50
3.6.3 Confirmability .................................................................................................. 51
3.6.4 Transferability .................................................................................................. 52
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusion</td>
<td>.................................................................</td>
<td>53</td>
</tr>
<tr>
<td>Chapter 4</td>
<td>Findings</td>
<td>54</td>
</tr>
<tr>
<td>4.1</td>
<td>Introducing the participants</td>
<td>54</td>
</tr>
<tr>
<td>4.2</td>
<td>Introduction: The nature of living with fluid restrictions, a summary of themes</td>
<td>56</td>
</tr>
<tr>
<td>4.3</td>
<td>Magnitude of loss</td>
<td>59</td>
</tr>
<tr>
<td>4.3.1</td>
<td>Social loss</td>
<td>62</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Loss of freedom</td>
<td>65</td>
</tr>
<tr>
<td>4.4</td>
<td>Constant struggle</td>
<td>70</td>
</tr>
<tr>
<td>4.4.1</td>
<td>Surveillance</td>
<td>76</td>
</tr>
<tr>
<td>4.4.2</td>
<td>Maintenance</td>
<td>79</td>
</tr>
<tr>
<td>4.4.3</td>
<td>Downsizing</td>
<td>82</td>
</tr>
<tr>
<td>4.5</td>
<td>Accepting</td>
<td>84</td>
</tr>
<tr>
<td>4.5.1</td>
<td>Life worth living</td>
<td>87</td>
</tr>
<tr>
<td>4.5.2</td>
<td>Support</td>
<td>88</td>
</tr>
<tr>
<td>4.5.3</td>
<td>Consequences</td>
<td>93</td>
</tr>
<tr>
<td>4.6</td>
<td>Summary</td>
<td>97</td>
</tr>
<tr>
<td>Chapter 5</td>
<td>Discussion and conclusion</td>
<td>99</td>
</tr>
<tr>
<td>5.1</td>
<td>The nature of living with fluid restrictions: Physiological and psychological loss</td>
<td>101</td>
</tr>
<tr>
<td>5.2</td>
<td>Attempting to ameliorate the struggle: Management and coping strategies</td>
<td>106</td>
</tr>
<tr>
<td>5.3</td>
<td>Reframing, accepting and managing a modified life</td>
<td>110</td>
</tr>
<tr>
<td>5.4</td>
<td>Implications and recommendations</td>
<td>116</td>
</tr>
<tr>
<td>5.5</td>
<td>Recommendations for future research</td>
<td>119</td>
</tr>
<tr>
<td>5.6</td>
<td>Expected outcomes</td>
<td>121</td>
</tr>
<tr>
<td>5.7</td>
<td>Study limitations</td>
<td>121</td>
</tr>
<tr>
<td>5.8</td>
<td>Conclusion</td>
<td>122</td>
</tr>
</tbody>
</table>

References ................................................................. 125

Appendix 1: Summary of studies in literature review ........................................ 134
Appendix 2: Hunter New England ethics approval letter .................................... 144
Appendix 3: University of Newcastle ethics approval letter ................................ 145
Appendix 4: Information letter ............................................................................ 146
Appendix 5: Consent form .................................................................................... 149
Appendix 6: Interview schedule .......................................................................... 150
Appendix 7: Abbreviations .................................................................................... 152
Table of Figures
Figure 3-1: Study process ........................................................................................................ 39
Figure 4-1: Summary of results with three superordinate themes and eight sub-themes .................................................................................................................................................... 58
Table of Artefacts

Artefact 4-1: Happy times ................................................................. 64
Artefact 4-2: ‘I remember how thirsty we were’ ........................................ 66
Artefact 4-3: ‘Happy hour’ .................................................................. 66
Artefact 4-4: The salt ............................................................................ 67
Artefact 4-5: These were ‘just’ out of a magazine ..................................... 67
Artefact 4-6: The things I can’t do anymore ........................................... 67
Artefact 4-7: ‘Restricted’ ....................................................................... 69
Artefact 4-8: The man in the desert ....................................................... 73
Artefact 4-9: I’ve got a 120ml cup, that’s my tea cup and I’ve got a 70ml glass .... 83
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?