Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

A TABLE OF METAPHORS:

THE VISUAL REPRESENTATION OF CHRONIC ILLNESS

A thesis presented in partial fulfilment of the requirements for the degree of

Masters of Arts
In
Social Anthropology

At Massey University, Albany
New Zealand

Ruth Elizabeth Anne Gibbons

2010

ABSTRACT

For people who live with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity syndrome illness is a hidden construct. The body does not display the chronicity of the internal experience. This thesis removes the barrier between what is experienced and what is visible by creating visual means of communicating the body's hidden experience. The place of the viewer is part of this discussion. Through visual methods digital photographic techniques and the current interest in sensory anthropology the embodied sensory chronic illness experience is explored. The hidden experiences were made visual creating "MeBoxes" and masks which showed both the external and embodied internal experiences of chronic illness.

As the process of working with and walking beside the participants developed, I found that the discourse on imaging within the literature was inadequate to show the real lived experiences of those with chronic illness. My interactions with the people of this thesis and the process of honouring their experiences required a model that would encourage the viewer to new and perhaps unrealised depths of participation to understand the participant's multi-faceted and multi-layered experiences. Part of the discussion is the ability of images to communicate sensory experience as is the case with Munch's *The Scream* and Picasso's *Guernica*. Through the use of a hypertextual self-scape I show how participants created access to their experiences through their visual representations and through a collaborative approach became composite hypertextual self-scape metaphors.

ACKNOWLEDGEMENTS

I would like to begin by thanking my participants for their involvement in this unusual process. Your enthusiasm for the project and your willingness to share your experiences has made this thesis possible.

Thank you to the Graduate Research Fund at Massey Albany who made it possible for me to do this research through their financial support.

Thank you to the Association of Social Anthropologists New Zealand's Kakano Fund Award for their financial support in printing this thesis.

Thank you to my supervisor Dr. Eleanor Rimoldi who supported my unusual research method and encouraged me throughout the process. To my second supervisor Dr. Kathryn Rountree who encouraged me to polish my thesis and make it shine. I would also like to thank my markers for their supportive comments and encouragement.

Last but not least my family who have supported me throughout the ups and downs of the thesis process and especially to my proof reader and sanity supervisor, also known as Mum.

CONTENTS

LIST OF ILLUSTRATIONS	
CHAPTER 1 – INTRODUCTIONPg TOPIC AND APPROACH	1 1
CHAPTER OVERVIEW	2
PERSONAL INTEREST	5
RESEARCH FOCUS	6
CHAPTER 2 - WORDS AND VISIONPg. WHAT IS CHRONIC ILLNESS?	7 7
VISUAL ANTHROPOLOGY	13
WHY THE VISUAL IN RELATION TO CHRONIC ILLNESS	16
COMMUNICATING THROUGH THE VISUAL	20
LOOKING IN: VISUAL IMAGES AND SEEING	22
IMAGES AND ART	23
THE POLITICS OF VISION	25
SUMMARY	27
CHAPTER 3 - METHOD AND PRACTISEPg. CARE OF PARTICIPANTS	29 30
SUPPORT GROUPS	31
INTERVIEW SESSION ONE :"MeBOX"	36
MASKS	40
INTERVIEW SESSION TWO: PHOTOGRAPHIC METHOD	42
PHOTOGRAPHIC PRACTICE	43
THE MISSING	44
IMAGES OF CHRONIC ILLNESS	45

CHAPTER 4 - OBJECTS, NARRATIVE AND HYPERTEXT.PG. 47

46

SUMMARY

47
48
53
60
66
71
76
_F- 77 77
7 <i>1</i> 78
86
94
110
110
OND THE
OND THE 111 112
111
111 112
111 112 113
111 112 113 115
111 112 113 115 117
111 112 113 115 117 118
111 112 113 115 117 118 122
111 112 113 115 117 118 122 125
111 112 113 115 117 118 122 125
111 112 113 115 117 118 122 125 186
111 112 113 115 117 118 122 125 186 189 190
111 112 113 115 117 118 122 125 186 189 190

CREATIVITY, MEDICAL ANTHROPOLOGY AND VISUAL ANTHROPOLOGY

199

APPENDICES

TERMINOLOGY

BIBLIOGRAPHY

LIST OF ILLUSTRATIONS

CHAPTER 3	Image 3.1 Image 3.2 Image 3.3	Pg 34 Pg 38 Pg 40
CHAPTER 4	Figure 4.1 Figure 4.2 Figure 4.3 Image 4.1 Image 4.2 Image 4.3 Image 4.4 Image 4.5 Image 4.6 Image 4.7 Image 4.8 Image 4.9 Image 4.10 Image 4.11	Pg 51 Pg 52 Pg 62 Pg 63 Pg 64 Pg 66 Pg 67 Pg 68 Pg 69 Pg 71 Pg 72 Pg 74 Pg 75 Pg 76
CHAPTER 5	Image 5.1a Image 5.1b Image 5.2 Image 5.2a Image 5.2b Image 5.2c Image 5.3a Image 5.3a Image 5.3b Image 5.3c Image 5.4c Image 5.4a Image 5.4a Image 5.4c Image 5.5 Image 5.5 Image 5.5a Image 5.5c Image 5.6c Image 5.6c Image 5.7 Image 5.7a	Pg 81 Pg 98 Pg 99 Pg 82 Pg 90 Pg 100 Pg 101 Pg 84 Pg 93 Pg 102 Pg 103 Pg 104 Pg 105 Pg 104 Pg 105 Pg 85 Pg 106 Pg 107 Pg 86 Pg 107 Pg 86 Pg 109 Pg 109 Pg 89 Pg 110

Image 6.1 Image 6.2 Image 6.3 Image 6.4 Image 6.5 Image 6.6 Image 6.7 Image 6.8 Image 6.9 Image 6.10 Image 6.12 Image 6.12 Image 6.13 Image 6.14 Image 6.15 Image 6.16 Image 6.16 Image 6.17 Image 6.18 Image 6.20 Image 6.20 Image 6.21 Image 6.22 Image 6.23 Image 6.24 Image 6.25 Image 6.26 Image 6.27 Image 6.28 Image 6.29 Image 6.30	Pg 129 Pg 130 Pg 137 Pg 137 Pg 137 Pg 138 Pg 143 Pg 144 Pg 145 Pg 150 Pg 150 Pg 156 Pg 156 Pg 156 Pg 163 Pg 167 Pg 167 Pg 167 Pg 168 Pg 167 Pg 168 Pg 173 Pg 180
Image 6.31	Pg 181
The Scream	Pg i Pg ii
	Image 6.2 Image 6.3 Image 6.4 Image 6.5 Image 6.6 Image 6.7 Image 6.8 Image 6.9 Image 6.10 Image 6.12 Image 6.12 Image 6.13 Image 6.15 Image 6.15 Image 6.16 Image 6.17 Image 6.18 Image 6.20 Image 6.21 Image 6.21 Image 6.21 Image 6.22 Image 6.23 Image 6.24 Image 6.25 Image 6.25 Image 6.26 Image 6.27 Image 6.28 Image 6.29 Image 6.30 Image 6.31 "MeBox"