



BODY MAPPING WITH GERIATRIC
INPATIENTS RECEIVING DAILY HÆMODIALYSIS
THERAPY FOR END-STAGE RENAL DISEASE
AT TORONTO REHABILITATION
INSTITUTE: A QUALITATIVE STUDY

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A Thesis Submitted to the School of Graduate Studies
in Partial Fulfillment of the Requirements for
the Degree Master of Arts

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MASTER OF ARTS (2012) Hamilton, Ontario (Health & Aging)

TITLE: Body mapping with geriatric inpatients receiving
daily hæmodialysis therapy for end-stage renal disease at Toronto
Rehabilitation Institute: A qualitative study. AUTHOR: Bryn A. Ludlow,
B.F.A. (Ontario College of Art & Design University) SUPERVISOR:
Professor C. Sinding. NUMBER OF PAGES: ii, 184

This thesis document is prepared using the referencing style of the American Psychological Association (APA), 6th edition.

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ABSTRACT

The innovative research method of “body mapping” was used in this study with geriatric inpatients receiving daily hæmodialysis therapy for end-stage renal disease at Toronto Rehabilitation Institute. The aim of doing body mapping with this population was to discover how it might give voice to their illness experiences.

Five people took part in this study. All completed at least one body map, and three completed all study phases: they created three body maps each and took part in one follow up, semi-structured interview to share their experiences of body mapping. Two themes were drawn from the data: (1) body mapping gives patients a voice to communicate their experiences in the dialysis unit; and (2) body mapping makes visible participants’ illness adjustment patterns, and levels of connection, or disconnection in the dialysis unit.

Participants drew, named, numbered and labelled their pain and cramping sensations; they wrote about socio-cultural experiences on, and around their body maps, drawing family members and their nephrology team members. Some planned to continue body mapping on their own time. The maps allowed participants to make their health concerns visible all at once; these accounts were tracked over time on the maps. Body mapping revealed participants’ illness adjustment patterns in response to their hæmodialysis therapy, which addressed their independent understanding of their health—their voice.

Participants seemed to attend to the deeper needs of their bodies, realizing that they have the ability to describe and share their experiences, rather than letting things go and ignoring sensations of pain. Based on the ways body mapping benefitted participants in this study, it is reasonable to suggest that this visual communication tool could be useful in other research settings, and as a clinical tool to support patients’ attention to their bodies and their interactions with healthcare providers.

Keywords: body mapping, hæmodialysis, end-stage renal disease geriatric health, arts-based inquiry, illness adjustment patterns

ACKNOWLEDGMENTS & DEDICATION

I would like to express sincere appreciation to Dr. Chris Sinding for her assistance in the preparation of this manuscript. Her approach to translational and representational analysis of images in context of health experiences is inspiring and a great match with my thesis work. Thanks to committee members, Dr. Amanda Grenier and Dr. James Gillett for providing invaluable feedback in this process. Thank you to Kristine Espiritu in the Department of Health, Aging & Society for her excellent administrative support and superior organizational skills.

I am grateful for the financial support of the Sir Edmund Walker Award and to the participation of the adjudicators: Pixie (Mudge Massey) Shaw, Professor Beth Alber, and Professor Ian Carr-Harris. Thanks to representatives of the Scholarships & Awards committee at the Ontario College of Art & Design University, including Professor BH Yael.

At Toronto Rehabilitation Institute, University Centre: thanks to Tracey Dion, Therapeutic Recreation for collaboration during the research ethics application and data collection phases. Thanks to Lesley Wiley, Program Manager of Unit 6-South, for approving the project, and to Dr. Ron Keren of Geriatric Psychiatry for being available for patient consultation. To the staff of 6-South at Toronto Rehab, and the staff in the Dialysis Unit for their acceptance and assistance in the process of data collection. Thanks to the Research Ethics Boards at Toronto Rehabilitation Institute and McMaster University for your reviews, and approval of this study. I am indebted to the participants for their voluntary participation and outstanding contribution to this thesis.

I am thankful for the ongoing support of my former professor and mentor, Professor Martha Ladly (OCADU) for always encouraging me to pursue my dreams in university. I am also appreciative of the design perspective of my former professor, Professor Doreen Balabanoff; to Dr. Allison Crawford, and Art Therapist, Suzanne Thomson for their consultation on the study data. Thanks to Professor Anju Joshi, for her mentorship in the field of gerontology, and excellent teaching supervision at McMaster University.



I dedicate this work to my mother. I am grateful for your unconditional love and support in my life and with this work: putting chalk in my hand, and an easel in front of me; never giving up; teaching me the skills of persistence and dedication; and always encouraging me to continue my education.

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LIST OF ABBREVIATIONS

HD Hæmodialysis

ESRD End-Stage Renal Disease

TRI* Toronto Rehabilitation Institute
*Also, “Toronto Rehab”

IAT Illness Adjustment Type(s)



*Participant names have
been changed to
protect their privacy
and confidentiality.*

INTRODUCTION

This Master of Arts thesis research study was designed with the interest of understanding how geriatric inpatients with End-Stage Renal Disease (ESRD) receiving daily hæmodialysis (HD) therapy at Toronto Rehabilitation Institute (TRI/ Toronto Rehab) give meaning to their experience of hæmodialysis therapy using a qualitative health research method called, “body mapping”. The research question asked, “Does body mapping give geriatric inpatients with ESRD receiving daily hæmodialysis therapy a voice to communicate their sensations, pain and experiences?”

Following 4.75 years of volunteering at Toronto Rehab with this population, I heard and witnessed participant’s stories about dialysis therapy: feeling cold, and having pain in specific areas of the body at different times during treatment. These accounts are echoed in the literature about patients' responses to dialysis therapy. Yet my interest and questions remained, about how participants cope with their hæmodialysis therapy, before, during and after each session; I wanted to learn how participants understand their complete bodily experiences, and discover a broad picture and account of their therapy. The method of body mapping turned out to be a high-quality approach to discovering the participants’ experiences by literally, and metaphorically drawing from their sensations and experiences of their bodies.

Chapter 1: Literature Review

Literature supporting this thesis research is framed by two core themes: body mapping: history, theory and applications; and illness adjustment patterns associated with experiences of hæmodialysis therapy and end-stage renal disease. In this review, I found material to support the analysis and observations from the study data, learned how these issues have been approached in the past, and found more gaps worthy of exploration for future studies.

BODY MAPPING: HISTORY, THEORY & APPLICATIONS

In its most basic definition, body mapping is a research method, and methodology for exploring thoughts, sensations, pain, and emotions, in and around the body on a paper or in digital format as a way to give voice to life experiences, including: health, work, education, social/ family life. There are four distinct approaches to body mapping research and practice in the literature, including: physiological, experiential, psychosocial, and theoretical.

A form of navigation of life experience involving the body, it has been done one on one or in groups with one full-sized map over three to five sessions, or with three to five small-scale maps in three to five sessions. However, the form of body mapping is contingent on the population that will

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do the mapping, and the approach that the researcher/ facilitator chooses to undertake. Likewise, the approaches can be combined in one body mapping research study, or community-based project.

After a body mapping study is complete, if participants wish to continue the process on their own, they can continue body mapping, or use the more practical and personal format of “tracing books” (Morgan, n.d.). This involves photographing the original body map, printing it onto standard letter-sized paper and placing it into a pad of tracing paper where participants can do mapping on a regular basis, or over a period of three or more consecutive weeks (Morgan, n.d.).

However, in the research literature, the current definition of ‘body mapping’ is floating: many authors and practitioners have taken up the practice, but have not identified it as a research method, with guidelines on how to incorporate it into a research study. It has been incorrectly named a methodology— it is not solely a way of thinking about research— it is also a method. Boydell, Gladstone, Volpe, Allemang & Stasiulis (2011) note the importance of making this distinction between ‘method’ and ‘methodology’ clear in the arts-based research community; the terms are frequently confused as meaning the same thing, but they have different purposes canonized in research design.

This is a chronological review of body mapping research from 1987

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to the present, which has found that body mapping is a measurable creative art method; it can be used as a diagnostic aid; it is expressive, and can be therapeutic. It blends art and medicine in the area between the medical model and complementary medicine, and can be used across disciplines. It is likely that other body mapping work is, and has taken place in pilot projects, and community groups; however, only peer-reviewed articles and a major web-based project, “Art2Be” (Verhoest & Schwalbe, 2012) are included.

ORIGINS AND AUTHORSHIP OF BODY MAPPING

This issue of acknowledging original authorship comes into play in many works after Andrea Cornwall’s article in 1992. Her article builds on MacCormack and Draper’s 1987 chapter on mapping gynecological health concerns of women living in rural Jamaica, and it inspired Cornwall to bring the practice to women in Southern Zimbabwe (1992). Following an exhibit of body maps in 2002 that were created in 2000 with Jonathan Morgan, graphic artist Jane Solomon published a facilitator’s guide to body mapping, which was ground-breaking in both research and grassroots organizations, as it made the practice available to practitioners in health and the arts (2007). However, Solomon did not coin “body mapping,” as many preceding authors suggest.

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McCormack and Draper (1987) and Cornwall (1992) named their practice “body mapping” and Cornwall discussed it as a “research method,” but did not elaborate on why and why it needs to be established as such; this was likely a given to Cornwall, because she is a researcher and does participatory action research work. Solomon’s contribution was to design a facilitator’s guide involving “full-body” body mapping (2007). She designed the most comprehensive how-to guide, or white paper on the activity of body mapping in collaboration with Jonathan Morgan, but the written work about body mapping originates in MacCormack and Draper’s research with women living in rural Jamaica (1987).

Before MacCormack and Draper’s chapter, where they asked participants “to draw their reproductive system and explain how it functioned,” psychologists used other similar drawing tests such as the “House-Tree-Person (HTP)” test as a diagnostic tool to find out if their clients might have a personality disorder (Hammer, 1954). This HTP test was controversial, as the measures used to diagnose people based on their drawings were too narrow and too subjective (Hammer, 1954).

MacCormack and Draper’s approach is similar to the HTP test, but without the house and tree, and Cornwall’s analysis builds on the method following MacCormack and Draper’s study. However, this still leaves a gap between Cornwall’s study in 1992, and Solomon’s comprehensive body

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mapping design in 2002. My deduction is that there was very little use of arts-based research in qualitative studies similar to the work of MacCormack and Draper, and Cornwall in that ten-year period. When Solomon and Morgan collaborated, they might have looked at the literature by MacCormack and Draper, and Cornwall, or they might have approached their project just as they say in the introduction of their guide, “Jane is responsible for the design of the core of this particular body mapping sequence” (2007, ii).

My primary conclusion is that Solomon and Morgan likely tailored the body mapping work to their population of people living with HIV/AIDS, who have very complex health issues, as well as to the social, economic, political, cultural, and psychological concerns that affect their bodies and care; the authors sought to contain these aspects of life in one modality. As a result, it turned out that the approach of body mapping was highly successful, and knowing about MacCormack and Draper (1987), and Cornwall’s (1992) previous research helps understand Solomon’s (2007) work, as well as other research involving the method of body mapping.

APPROACHES

In the literature, I found four core approaches to body mapping: physiological, experiential, psychosocial, and theoretical approaches. The articles in this review are grouped into these approaches as a means to organize the review, and to address the gaps in the literature, as there are only twelve peer-reviewed sources on body mapping work. I found that though body mapping research is not new, it is emerging in the social sciences and medical research as a formal research method. Authors have drawn from each other's works, specifically that of Solomon (2007), but have not formally grounded it as a research method.

PHYSIOLOGICAL

The physiological approach is named as such because the body mapping work that fits with this approach involves identification and labelling of bodily forms, systems and structures, compared to exploration of emotional experiences. Blakeslee and Blakeslee (2008) found internal connections with body mapping in the neurological system called, “peripersonal space” which is essentially the space around your body. This “brain mapping” relates with body mapping, as they note, “Your self does not end where your flesh ends, but suffuses and blends with the world, including other beings” (2008, p. 3).

In many body mapping sessions, participants will draw inside and outside of their bodies, and this might be because of their “elastic sense” and peripersonal space, and in the physiological approach, future research can explore this emerging field (2008, p. 3). Blakeslee and Blakeslee call this ‘peripersonal space,’ “body maps,” but because of the focus of the book, they do not discuss how people can make visible maps of their bodies from these inherent body maps, as in the method of body mapping (2008, p. 3). In the body mapping literature, the approaches are often mixed together. The intent of all body mapping work is not always to label specific body forms, systems and structures, but there is merit to the physiological approach for studies requiring a deeper understanding of how participants identify their bodily forms.

Using a stick in the ground, and paper when available, anthropologists MacCormack and Draper introduced the practice of body mapping to women living in rural Jamaica to learn how they name their gynæcological and gastrointestinal systems (1987). They continued body mapping using paper and pencil with female university students in the UK and US to compare images and physiological renderings of their bodies— a cross-cultural comparison study (MacCormack & Draper, 1987).

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In this study, the rural Jamaican women's drawings were very different from the American and UK women's drawings, and this was fundamentally because of the participants' socio-cultural experiences and education about human anatomy (1987). The drawings of the uterus are particularly intriguing, as the US and UK drawings are close to anatomical textbook quality, and some include drawings of their Intra-Uterine Devices (IUDs) (MacCormack & Draper, 1987). In-contrast, the rural Jamaican women's drawings of their uterus' represent their spiritual understanding of the process and cultural importance of giving birth: the uterus drawings take up much of their lower abdominal space, where in reality it is no larger than half a fist (MacCormack & Draper, 1987).

In this study, the rural Jamaican women “knew their bodies as “regions,” not “parts of a whole,” and they used social terminology to name these body regions:

The interior space from the neck to the bottom of the ribcage is the ‘stomach’ and the large soft cavity below that is the “belly.” The lower part is the “belly bottom.” (MacCormack & Draper, 1987, p. 159).

Cornwall (1992) does not specifically state in her article that she came up with the name, “body mapping” as a response to this regional mapping by the rural Jamaican women, but this might be the case, as the rural Jamaican women in this study named the regions of their bodies as a cartographer would when mapping a city. Though it is common in anthropological

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research to engage in cross-cultural studies, this study by MacCormack and Draper (1987) is worthy of repetition, but with the more developed body mapping design by Jane Solomon (2007). The benefit of a cross-cultural study with body mapping would be the ability to literally go beyond borders to other countries, making more of a generalized analysis about the human experience with the method of body mapping.

In 1992, participatory action researcher, Andrea Cornwall published a short paper on her work with women in Southern Zimbabwe, and on the intent of her work. She states, “We used maps of the body to share our versions of anatomy and physiology” (1992, p. 1). A key contribution that Cornwall makes to the method of body mapping comes from her perspective as a participatory action researcher where she interviewed the maps to “avert biases about shared referents,” moreover, “the map acts merely to generate themes for further commentary” (1992, p. 4-5).

Challenges in learning about the details of participants’ maps might arise when only asking for descriptions about participants’ maps, as Magalhães (presenter) noted was experienced in her study with Gastaldo, Carrasco, & Davy (2010a). So by interviewing the maps, as Cornwall says these, “biases are averted,” and the truth about the images in the maps is shared between the participant and interviewer (1992, p. 4). In both Cornwall and MacCormack and Draper’s research, they facilitated body

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mapping sessions that focused on one area of the body, which is interesting, as this can be replicated by other specialists interested in other areas of the body, such as the joints, for a rheumatologist.

A form of body mapping has been used in contemporary dance as “pain mapping” by researchers, Jenn Tarr and Helen Thomas of the London School of Economics (2011). This work involved an innovative process of 3D body scanning, and follow-up interviews with the dancers (Tarr & Thomas, 2011). The images of the dancer’s bodies were presented on a screen where they used a stylus to draw on their images where they experienced pain from the rigors of dancing; they could use different colours, but only one choice for stylus drawing thickness (Tarr & Thomas, 2011).

In the images, you can see the back, front, right and left side of the dancer; the scanner only captured part of the head, and cut off the bottoms of the feet (Tarr & Thomas, 2011). In the literature, the body mapping images that I reviewed to-date only involved images of the body from the front. The image by Tarr and Thomas shows markings at the same location in one profile as the others (2011). For example, the pink circle around the blue circle on the knee on the front profile is seen in the same anatomical location as the pink and blue circle on the knee in the right profile. This happened because there was a single, manually rotating 3D body image that the dancer/artist painted on, and then the markings were presented with these

four profiles (Tarr & Thomas, 2011). The benefit of this imaging technique is that it accurately shows where the dancer experiences pain, similarly to an x-ray, but drawn by the participant.¹

The reasoning behind Tarr and Thomas' 3D design is so that health care providers can see the landmarks on the figure where the dancers' pain is located as accurately as possible (2011). Having said this, when the 3D image is printed on 2D paper— in the case of a research report— the perceptual experience is the same for the reader, dancer, and researcher, and so this begs the question of the value of using the 3D image technology at all, if it looks the same as a 2D printed image.²

Returning to the original idea of body mapping, where a participant maps their pain, sensations, thoughts, emotions onto an outline of their body, or a representative outline of their body, 3D pain mapping is slightly removed. It is a highly medicalized form of body mapping that aims to tell a

¹ I considered introducing these four profiles to my work with hæmodialysis patients who have End-Stage Renal Disease, but this 3D technology was not readily available, and so I thought it would be difficult for the patients to repeat the same marking on the second, third and fourth profile. The markings might turn out to be inaccurate accounts of their experiences after creating the first marking. However, I agree with Cornwall's thought that, "it makes little sense to 're-educate' people if their ideas are not harmful (1992, p.6)." A suggestion by Dr. Catherine Phillips of Lakehead University following my presentation at the University of the Witwatersrand in Johannesburg, South Africa in November 2011 was to use the back of the body mapping paper if a patient wanted to elaborate on a specific area in more detail, or if they felt confined to the body mapping template. After completing one map with the first participant, I kept this option in-mind, but no patient wanted to explore mapping in this way.

² In my study, Carmine had great insight from her observations as a participant in the body mapping sessions, and suggested that it would be useful to have a 4-dimensional body to map on, similarly to a doll, where participants could move the figure and map their experiences, sensations and pain on the 4D form.

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physician, or other health care provider exactly where it hurts so that a diagnosis can be made. Body mapping in its pure form is more open, and works as a navigation tool for people to point to their pain, and label their sensations, thoughts, experiences, but not necessarily with the goal to change it.

Nevertheless, in Tarr and Thomas' study, the dancers appreciated being able to recognize any misalignments to their bodies, and patterns of injury on one side, or area of their bodies so that they could pay more attention; it, "made it easier to see what they needed to work on" (2011, p. 149). In Tarr and Thomas' work, four participants had "blind spots," on their bodies where they could not name their pain (2011, p. 149); a similar phenomena occurred in my study, and is discussed in the findings section.

Some of the participants in Tarr and Thomas' study said they found the scanning process "objectifying and even disembodiment," because of the very accurate depictions of their bodies, which also identified socially constructed "flaws" of body proportion (2011, p.151). The authors did not recommend using a computer or body scanner for these reasons. Though the technology failed, it does not necessarily mean that the technology fails, and should be abandoned altogether. Future iterations could address these impersonal interactions with the computer and scanner that would make the experience more comfortable for the participants.

EXPERIENTIAL

Body mapping work that fits with the “experiential” approach does so because of the work aimed at encouraging experience building, self-expression, and connection to the body as the self, and to others in the same space. Therefore, it often, but not always involves group-based mapping.

This broad perspective allows for flexibility in future work to break apart the approach into sub-themes, or new approaches with new work. The articles selected for this approach do not fit tightly into the other approaches, such as physiological or the psychosocial approach, and this is largely because of the multilayered, narrative experience sharing qualities of the body mapping research. Solomon’s “Living with X” is a guiding work for many of the articles that follow; it is similar to dropping a stone into a cone-shaped pile of chalk, where the chalk reacts to the stone by dispersing widely into all cracks and crevices of a table (2007). The works in the experiential approach connect to interdisciplinary areas of life, including: socio-economic, cultural, historical, and psychosocial health.

In 2006, Solomon produced a guide, “Living with X: A body mapping journey in the time of HIV/AIDS—facilitator’s guide,” and it was made available in North America in 2007. The Regional Psychosocial Support Initiative (REPSSI) and the Canadian AIDS Treatment Information

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Exchange (CATIE) were the two key partners for the development of the guide, as well as Novartis Foundation for Sustainable Development, Sida/Asti (Swedish International Development Agency), and the Swiss Agency for Development and Cooperation (SDC). Her approach to body mapping was developed from her background in freelance design and skills training, and she developed 17 exercises for body mapping that she “recommends to complete in at least 5 sessions” (2007, p. 5).

The exercises were developed in collaboration with clinical psychologist, Jonathan Morgan, who contributed to the psychosocial aspect of some of the exercises (Solomon, 2007). The comprehensive guide contains lists of suggested materials to work with, possible challenges for both the facilitator and group members, safety guidelines, a sample informed consent form, and a version for use of the maps in public, and the steps to create a body map (Solomon, 2007).

Solomon’s technique for creating the body outline is in partners: one person lies down on the paper where they will map; the other traces their outline (2007). The first tracing is of the partner: the second tracing is of the person creating the body map (Solomon, 2007). The intent of using two outlines is so that the participants feel supported by each other. Another unique aspect of Solomon’s approach is to use hand and feet prints by putting pigment on the hands and feet, then stamping it on the paper where the hands

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and feet are located (2007). This practice is an “ancient form of mark-making that people used to show their presence in the world,” and it is an early step in the guide, which also seeks to establish connection between the map and body (Solomon, 2007, p. 21).

The other steps in the guide are very focused and specific, and seem to be designed based on the psychosocial perspective from Jonathan Morgan; along with the exercises, there are “challenges and tips” for overcoming them, which is helpful for someone who is not familiar with body mapping, or does not have arts-based facilitation training (Solomon, 2007, p. 26).

Solomon notes, “The “X” in “Living with X” involves learning about “several points of view about their lives, their special qualities, their story and their body map” (2007, p. 52).

Distinctive to Solomon’s work is this exercise, where participants reflect on each other’s maps; they use this phrase, “When I see ___’s body map, I see a person who is living with X and X” and they write it down for each member of the group on a separate piece of paper, then share their writing with the group (2007, p. 52). This form of group reflection is a way for the members of the group to think about how others have expressed themselves in the maps, to see similarities, make connections and support each other with the challenging stories people share on their maps (Solomon, 2007).

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Morgan discusses important work by Subotzky & Hwele who responded to the body mapping work in 2003, by Solomon and Morgan's exhibition in 2002 (Morgan, n.d.). They facilitated body mapping sessions with 18 participants who had HIV, or AIDS prior to the availability of Anti-Retro Viral (ARV) therapy, so their two themes responded to this circumstance of, "no access to treatment," and "hopelessness" (Morgan, n.d.). Anya Subotzky was inspired to give participants the opportunity to continue body mapping, so she designed 18 tracing books with tracing paper so that the participants could layer their maps and see patterns over time (Morgan, n.d.). Morgan defines "tracing books" as:

One scaled down version of the life sized body map and a sheaf of blank pages made of transparent tracing paper, make up the hand bound patient held file in which the patient is able to track and communicate ongoing physical and emotional changes in his or her body and mind. (n.d.).

Morgan later addresses the issue of confidentiality and privacy with life-sized body maps, and so the tracing books act to protect the patient/participant, as well as function as a journal for them to continue body mapping independently, or with their care team (n.d.).

Verhoest & Schwalbe were also inspired by Solomon & Morgan's exhibit in 2002, and they established the web portal for body mapping based in Northern Europe and South Africa called, "Art2Be" in 2005 (<http://www.art2bebodymaps.com/>). Though no peer-reviewed sources discuss their project, they have an extensive and well developed website that

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follows similar facilitation procedures by Solomon (2007). They write that their approach to body mapping is in “art therapy,” which compared to other body mapping projects that are based in “therapeutic arts,” is more rigid and involves evaluation of the work created by participants to assist them with their healing.

Though body mapping is a form of therapy, my approach to it with participants in this thesis study was with a therapeutic lens, not as a diagnostic tool used in art therapy. However, in Kenya where Art2Be is based, it is possible that the participants/ clients need a diagnostic tool if they do not have another option for care. Especially if they live in rural areas that are far from a medical clinic such as the “most at-risk populations (MARPS),” and they can use body mapping to keep track of important health changes that need attending to by a physician or nurse once they are able to come to the clinic (Verhoest & Schwalbe, 2005).

Additionally, their website allows for open communication about their projects and for dissemination of their results to participants, clinics, art galleries and other countries wishing to experience and practice body mapping, which is important for passing on knowledge about the method (Verhoest & Schwalbe, 2005). They have exhibited the body maps in England, and have run workshops in Germany (Verhoest & Schwalbe, 2005). The expansion of their work with new populations is innovative, and gives a

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complete account of the experiences of these diverse populations through text and drawing.

Between 2005-2008, many projects branched off from Solomon's influential work, to new concepts and responses. The 2006 AIDS Conference in Toronto, Ontario featured Solomon's work in the Global Village at the Metro Toronto Convention Centre, and by this time, the practice was officially established as a suitable approach for allowing clients/participants to express their sensations and experiences, giving them voice in the medical community, with medical delegates visiting, and walking by the exhibit. I was fortunate to be working there, met Solomon, and this is where I first learned about body mapping.

In 2008, Devine published a review paper on the facilitation guide by Solomon (2007). In this, she speaks to the global impact of HIV/AIDS, and how body mapping has helped people express how they feel as a result (2008). In 2011, Blum travelled to South Africa to work with the Bambanani Women's Group that worked with Solomon and Morgan in 2000 for the body mapping project. Blum interviewed Solomon and the participants as part of her Master's thesis research based at York University, Canada. Her direction in this work was to "consider all 'traces and fragments' of this past in recovering the 'lost' history of South Africa" (Blum, 2011, p. 2). When speaking of "traces and fragments," she is referring to the memories

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participants in the Bambanani Women’s Group had of living in South Africa during Apartheid, and that the ‘traces and fragments’ of these memories could possibly be located in the body maps by exploring their experiences (Blum, 2011).

In November 2010 at the Visual Arts and Humanities conference at McMaster University, Lilian Magalhães of Western University (London, ON) presented results of body maps created from her project with Gastaldo, Carrasco & Davy (2010a) involving experiences of undocumented migrant workers in Canada. Later, on June 26, 2012, I attended a “research art exhibition” opening talk about their 20 body maps at Toronto City Hall.

The maps were copies of the original works, printed on translucent cloth. The benefit of this format was that it was easy to transport the 20 life-sized works, rolled up in a large tube. Another reason why they were printed from the originals, which might be useful for future work, is that they were able to remove any identifying information via the eraser in the computer program, Adobe Photoshop from the maps, as they needed to protect their participants’ confidentiality and privacy.

Each map was presented with a content key, with themes of: “colour, body posture, migration journey, personal symbol and slogan, marks on/under the skin, body scan and personal strength, support structures, future, message to others” (Gastaldo, Magalhães, Carrasco & Davy, 2012b).

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They used this key to frame their questions in the body mapping sessions, and by doing this, they could organize participants' responses under each item in their presentation.

They also had an inventory of images and symbols available for the participants to use, but they could also draw their own responses in a free-form way (Gastaldo et al., 2012b). Many used the image collection, and because of using the similar symbols and images across all participants, the authors were able to identify common themes across the 20 maps (2012b). This research design certainly saved time in-terms of organizing the data, and preparing the presentation, but I question if it might have been too rigid, and did not allow participants to explore their bodily experiences in a natural way.

Many participants used an image of a spine, or the spine with the gastrointestinal system, and they often drew arrows, or shaded areas in the spine where they experienced pain; it was usually in the lower spine area, likely from standing on the job for long hours. It was also interesting to me that they commonly drew stories about their travels just below their feet, as a representation of the steps they have taken. The future for many participants was either vague, or very clear, but many did not have a response to the question of “future” (Gastaldo et al., 2012b).

The participants also wrote on their maps inside and outside of their

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bodies, and the symbol of the heart was commonly presented inside and outside of their bodies. Many participants noted that the heart represented their relationships with friends and family, a social symbol common in other body mapping research in the experiential approach (Gastaldo et al., 2012b; MacGregor, 2009). They drew many hatched lines, outlines, and zigzags that were common in the body maps for my thesis study that represented pain, cramping and vague bodily sensations.

It was clear that these body maps were about sharing stories about work and labour, as there were many indications of hard hats, gloves, and other work-related symbols on the maps. As a viewer of the maps, I felt sad that this theme was so present, that the participants were expressing their experiences about their work, but that they were not adequately acknowledged by employers, or the country for the work that they do.

PSYCHOSOCIAL

Two projects focusing on the psychosocial aspects of body mapping took place in 2006 by Master of Counselling Psychology student, Tanja Meyburgh (University of Pretoria, South Africa) and four years later in 2010 by Psychiatrist, Dr. Allison Crawford (Mount Sinai Hospital, Toronto, ON). There are projects that connect to the method of body mapping, but are not

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named ‘body mapping’ that I will discuss in relation to these two works.

Contrary to other approaches to body mapping, Meyburgh (2006), and Crawford (2010) facilitated body mapping from the perspective of their roles as a psychology student (Meyburgh) and psychiatrist (Crawford) with clients and patients calling for psychosocial interventions.

Meyburgh (2006) and Crawford’s (2010) findings support the need for body mapping practice to expand into a third psychosocial approach, as participants found the use of the large-scale, life-sized body mapping overwhelming and triggered emotional dissociation associated with Post Traumatic Stress Disorder (PTSD) that was not helpful for their healing processes. The smaller scale maps acted to contain the participant’s responses to the process of body mapping, and made it easier to control and regulate their emotions (Crawford, 2010). This issue of disconnection from reality—dissociation— speaks to the need for body mapping work with a psychosocial approach, but also to the need for sensitivity when working with people who require emotional support during the process.

Tanja Meyburgh was a Master of Counselling Psychology student at the University of Pretoria (South Africa) and wrote a thesis titled, “The body remembers: body mapping and narratives of physical trauma” (2006). Her groundbreaking work in the area of body mapping with trauma survivors focused on interviews with “two men who were incarcerated and tortured for

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their political activities during Apartheid” (Meyburgh, 2006, p. 2). Since this was the first time body mapping was used in research with trauma survivors, she developed her thesis from the book by Babette Rothschild, “The body remembers: The psychophysiology of trauma and trauma treatment” (2000).

She facilitated two follow-up, unstructured interviews with the participants individually, and used a narrative analytical approach (Meyburgh, 2006, p. 2). She realized that “body mapping created the possibility for a different experience in their (participants’) lives to those of the past,” and it “gave them the opportunity to move from the isolation and exclusion of the past, into a place of community and inclusion” (Meyburgh, 69). My perception of “prisoner” was jaded until I visited the jail cells at Constitution Hill in Johannesburg, South Africa where so many people were unfairly jailed because of their political views during Apartheid. A quote by former President, Nelson Mandela written over a walkway leading to #4 and 5 captures this realization well, “It is said that no one truly knows a nation until one has been inside its jails. A nation should not be judged by how it treats its highest citizens, but its lowest ones.”

Meyburgh indicates, “neither of them spoke about the actual trauma experience...and body mapping did not bridge from narrative to narrative in the trauma experience,” which is different from Crawford’s (2010) results where participants found that body mapping re-triggered their memories

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(2006, p. 69). I assumed that with a small sample and unstructured interviews that Meyburgh would have heard about the participant's narratives of their trauma experience in more depth, but this speaks to the intensity of the participant's traumatic experiences that they were not able to share their stories. Regardless, Meyburgh gave these participants an incredible opportunity to be heard again, through drawing in body mapping.

A body mapping project with women with anorexia nervosa deepens our understanding of how body maps reveal (sometimes distorted) perceptions of reality. In a documentary film, "Dying to be thin," groups of young adult women are followed over a series of weeks in a cinema verité style of filming (McPhee, 2000). In one scene, a facilitator asked one of the women to draw their body outline on a piece of paper. After drawing the body outline, the woman is asked to stand against the same drawing and then the facilitator traces their true body outline. The image drawn by the female participant and the image drawn by the facilitator are very different: the participant's image is almost twice the size of their true body image.

This exercise is very similar to the initial outlining stage of body mapping, and it made clear for the participant what their reality is, versus what their perception is of their body image. The participant was very shocked and almost overwhelmed when they realized how much different their body outline was from the facilitator's true tracing (McPhee, 2000).

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Doing body mapping with people who have distorted perceptions of their body is therefore risky. Using a psychosocial approach might ensure that researchers/ facilitators are more accountable to participants who might have difficult, and unexpected responses to body mapping.

Crawford realized this risk in her work with people who were diagnosed with Post Traumatic Stress Disorder (PTSD) (2010). She found that by shifting to using the smaller tracing book body mapping, it worked to contain the participant's body experiences, and made creating their image more manageable (2010). Unique to other body mapping work, Crawford used guided relaxation and grounding techniques as follows, to help patients stay present before, during and after mapping:

Patients are instructed to pay attention to what happens within their own bodies as they work on the body maps. They are told to indicate the need for a 'time out' if their own bodily responses become too intense or if they feel they are becoming less present in their surroundings (i.e., dissociating). The therapist also encourages this approach by pausing in the process to inquire about current bodily states (such as asking, 'How are you feeling in your body right now?' and 'Do you notice any tension anywhere?'), and to do a scan of the body, further intervening with guided grounding or relaxation as necessary. (Crawford, 2010, p. 711).

This modality could be taken up in future body mapping research within the psychosocial approach, as it was successful to help participants stay present (Crawford, 2010). Her practice is very different from using tracing books with people who have HIV/AIDS, as the tracing books functioned as interventions: journals that the participants could take with them to work on

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in their own time (Morgan, n.d.).³ She used the small-scale maps to prevent experiences of dissociation with her patients who were overwhelmed by the process of creating the life-sized body maps, similarly to the response of female participants with Anorexia in the documentary film (McPhee, 2000; Crawford, 2010).

Though Crawford used tracing books in her study, she cautions against using body mapping as a health intervention, because of “maintaining therapeutic distance; the importance of patient: therapist boundaries; and straining the comfort level of a therapist who is not used to being physically close to patients” (Crawford, 2010, p. 716). However, she discusses how the field of psychotherapy does not traditionally use arts based methods (2010). Therefore, it is debatable if it would help reduce these tensions if the need for boundaries between patient: therapist is explained before beginning body mapping.

Most researchers working outside of the experiential approach used small-scale body mapping with participants. Crawford’s study was the first peer-reviewed body mapping project to use small-scale mapping while considering the full body, but MacCormack and Draper (1987), Cornwall

³ The small-scale format is also different in my study, where it was physically impossible for the patients to lie down on the floor and have their bodies traced, so the format was designed to meet the accessibility needs of the participants. I imagine that the large-scale maps pose a physical barrier for many other participants in body mapping work, and it might help to consider altering the scale of the maps to increase participation.

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(1992) and Morgan's (n.d.) work all involved small-scale mapping, so there is evidence in the literature for this approach. Maybe this is the direction body mapping is moving toward in future work?

Singh's reflection on our work as co-facilitators of a body mapping workshop offers further insight into the psychosocial approach of body mapping (2008). On June 23, 2008, Deborah Singh of the Toronto Rape Crisis Centre/ Multicultural Women Against Rape (TRCC/MWAR) and I co-facilitated a community-based body mapping workshop with queer survivors of sexual assault during Pride week in Toronto. With a small grant from Pride Toronto, we designed a body mapping workshop with reference to the work by Verhoest and Schwalbe (2005), and Solomon's (2007) work that was available online.

The workshop was held on one day and we invited six participants to do body mapping in a group. When planning the workshop, we looked at the maps by Verhoest and Schwalbe (2005) and Solomon (2007), and noticed that there were sometimes two body outlines in the maps.⁴ This was interesting for the population we chose to work with, because they often have physical and emotional experiences that are not always connected, but are perceived as occurring in layers. We also wanted the participants to realize

⁴ We didn't know why two outlines were used, as Solomon's guide was only newly released.

that they do have valid physical responses to their experiences of surviving sexual assault.

The group got into pairs to trace their bodies. The first tracing was of their bodies in an anatomical position, with their arms and feet out to the sides. The second image was a pose that the participants chose in that moment based on how they were feeling. The physical shift between each tracing shifted the mood of the participants, and of the room. Of the body mapping experience, Deb wrote, “I realized that I am my best resource and by putting it out on paper, through image and text, that it is really not my fault, and I am not alone” (Singh, 2008, p.6).

An interesting result of encouraging the participants to work with these two positions was that four participants drew their second image in a child’s pose, with their arms and knees tucked into their chest, indicating the need for comfort and safety. This might have been achieved by creating the maps. The other two participants only drew one outline; one drew her body as a tree, as an attempt to feel grounded through the body map drawing. The other drew her body running on the page.

It became evident in the process that this body mapping work was not helpful for half of the participants, as they drew representations of themselves that seemed to be very disconnected from their bodies. Though we held a debriefing session, it was voluntary to share experiences, and participants

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who shared spoke superficially about the positive aspects of their experiences, versus about their deeper experiences that were expressed in their body mapping, and body language. All participants expressed gratitude for the opportunity to share their experiences, and tune in to their bodies, but if the debriefing was one on one, or if we held more body mapping sessions, perhaps more participants would have shared what body mapping meant to them, including how they struggled, and how they worked through their experiences.

Even though some felt disconnected, they were able to realize this in the images, and possibly use their maps as a way to move forward, with reference for this time in their lives. Yet, as Crawford (2010) identified, it might have felt more safe in the moment for the participants to shift to work on a smaller scale body map that they could feel in more control with, versus the life-sized body map that revealed their life-sized pain, disconnection, and fear.

THEORETICAL

The theoretical approach is pertinent to researchers who write, or have written about body mapping, but have not facilitated body mapping in a community-based group, or conducted a research study involving the

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method. Their contribution to the literature is important, as it helps move the method forward by reflecting on the achievements and issues of body mapping to-date, as well as how to frame body mapping from a theoretical perspective.

The approach was explored in depth by three groups of researchers in Canada, South Africa and the UK: Hartman, Mandich, Magalhães, & Orchard (2011), Weinand (2006) and MacGregor (2009). Hartman et al. (London, ON, Canada) wrote about the use of body mapping as “a visual research methodology in the study of human occupation” (2011). Weinand (Cape Town, South Africa) explores the use of body mapping as an educational tool. MacGregor (Brighton, UK) considers the role of body mapping: its impact on the individual and society in South Africa (2009).

Hartman et al. built on the research by Cornwall (1992), Solomon (2007), and MacGregor (2009) and discuss how body mapping can benefit people receiving occupational therapy. They maintain, “Body mapping is an interactive way of exploring embodiment in occupational engagement” (2011, p. 299). As such, they found a limitation with the full-body size of Solomon’s body mapping, making the recommendation that “depending on participants’ age and general health, they should take breaks to ensure that they do not overexert themselves, and should regularly check how they are

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mentally, emotionally, and physically handling the process” (Hartman et al., 2011, p. 300).

Their paper presents an “instructional representation of the ‘*Living With X*’ body mapping process” (2011, p. 298). They have essentially developed a format for facilitation, and analysis of the maps with a sample body map showing numbers corresponding to instructions for facilitating a body mapping session, adapted from the list of exercises by Solomon (2007) (2011). As an arts-based research practice, this numbered system of approaching facilitation, and analysis of the maps by way of content analysis is a very helpful contribution to body mapping literature.

The authors name it an, ‘instructional representation’ but it could also be used as a guide for content analysis of the body maps to pull themes from the data. However, the breadth of the questions should be expanded so as not to frame the results by these questions alone. For example, they write on item 5, “Participants draw a self-portrait on the face of their body tracing,” but, as in other items in the list, I question why this happens (Hartman et al., 2011, p. 298)? After trying body mapping myself, I think the questions should be left more open, as it might be the case that in other body mapping projects, participants will not want to draw their portraits, or they might write or use symbolism to express how their head feels (Appendix E). Nevertheless, this

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‘instructional’ guide moves the process of interpretation of body mapping forward, showing evidence that the maps can be measured.

Weinand analyzes past approaches to education by the use of images; she notes, “The aim is to illustrate the extent to which the women’s knowledge about HIV/AIDS increased, as well as their ability to take action and transform their life situations (Weinand, 2006, p. 6).” She approaches theorizing body mapping using adult education theory, but from an “African context”, as her work is based in Cape Town, South Africa (Weinand, 2006, p. 6). Issues in her research were in finding barriers to “insider and outsider knowledge” about adult education of the body: medical treatment, and general experience, which is sometimes hailed from the outsider Western perspective, versus from the African perspective, and this “outsider versus insider knowledge (transfer)” in body mapping work was also found in Cornwall’s findings (1992) (Weinand, 2006, p. 10).

Weinand found benefits of body mapping to educate people living with HIV/AIDS (PLWHA) who were based in the community, because of the participatory nature of body mapping, which draws on “local knowledge for local action” (2006, p. 14). She also recognizes that body mapping naturally acknowledges, “Drawing and painting is a form of visual (non-verbal) communication” (2006, p. 14). She cites Karkou and Glasman (2004, p. 61) who note art production “involves the person as a whole, including sensor

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motor, perceptual, cognitive, emotional, social and spiritual aspects” (Weinand, 2006, p. 20). She also found that body mapping helped participants in the Bambanani Women’s Group communicate on maps of their bodies, their comprehension of their HIV status and treatment (2006).

Hayley MacGregor’s article reviews body mapping research as a means to clarify what exactly the benefits are of body mapping as a research tool and community intervention (2009). On review of the intent of Jonathan Morgan’s book, “Long Life” she found that the goal was for women to become “empowered” by the exercise of body mapping (MacGregor, 2009, p. 86). She later notes, “Claims of ‘empowerment’ are difficult to evaluate directly” (2009, p. 89). She does not clarify exactly why she feels this way, but suggests that it is because of the socio-political, and group-based dimension of body mapping in the community that seeks to empower participants, essentially, “socializing science” (MacGregor, 2009, p. 91). Her argument that body mapping functions in this way is an important contribution to the literature, and encourages further development of the method of body mapping in the social sciences.

Tracing the history of body mapping, finding the theories, and applications, has been a long journey, but a worthwhile investigation that will help future body mapping researchers take the method forward. Locating the four approaches and original authors in the literature gives researchers an

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opportunity to fill the gaps: to develop hybrid approaches, new specialties, and innovative directions for body mapping practice and research.

HÆMODIALYSIS, END-STAGE RENAL DISEASE, AND PATTERNS OF ILLNESS ADJUSTMENT

The literature on hæmodialysis therapy (HD) and End-Stage Renal Disease (ESRD) is complex and multifaceted. This review serves to provide a basic illustration of what HD and ESRD is, and how it affects people, to support the observations of participants in this study. The intent of exploring HD and ESRD is to understand the patient's experience of their HD therapy and experience of ESRD, not the clinical process of hæmodialysis in-detail; however, the basics of HD and ESRD are discussed here to support the analysis of the patient's health experiences in this study. The study data from each participant reveals a pattern of illness experience across each participant, and this is framed with the literature in patterns of illness adjustment, described by Radley and Green (1987).

HÆMODIALYSIS & END-STAGE RENAL DISEASE

Participants in this study require hæmodialysis therapy for 2 hours per day and 6 days per week (Sundays off) because their kidneys no longer do their

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job of balancing electrolytes, filtering blood, and producing urine; this is because of many reasons such as surgery, injury, infection or malfunction of other supporting organs (Stevens, Weiner & Weinstock Brown, 2009). Pierratos notes, “It is very expensive to do daily dialysis,” so the approach at Toronto Rehab is only a temporary intervention before patients transition to the community to do dialysis in hospitals as outpatients, or at home (2009, p.142).

It is important for older adults to be considered for hæmodialysis therapy if it is needed; Stevens et al. note, “many non-nephrology doctors do not recognize the signs in an older person that would give them the opportunity for dialysis” (2009, p. 538).⁵ If treatment is delayed, patients are at greater risk for developing end-stage renal disease (ESRD) earlier than they would if they started hæmodialysis therapy on time (Stevens et al., 2009). Having said this, ESRD also eventually develops following lower risk hæmodialysis therapy when caught on time—“end-stage”— so it is a catch-22, because the average survival of older adults (over age 65) on hæmodialysis therapy with end-stage renal disease is 1.5 years (Stevens et al., 2009).

⁵ It is also likely that many older adults do not communicate about their pain or discomfort associated with their kidneys early on.

Similarly, Stevens et al. question if “elderly dialysis patients have equal access to treatment, or if age is a reason for denial of treatment?” (2009, p. 548). However, they note that it should not be the only reason, as people age differently (2009). Pierratos also notes that many older adults are not given the opportunity for kidney transplant because of their age, even though their quality of life would be greatly improved (2009). This is not fair, and is a clear example of age-related discrimination (Novak & Campbell, 2010).

There are different methods of therapy to treat ESRD, but in Canada, “90% of patients use hæmodialysis therapy, versus 10% who use Peritoneal Dialysis,” which involves insertion of a catheter in the abdomen—the peritoneum (Stevens et al., 2009, p. 540).” Hæmodialysis is tolerated well by older adults, as they are able to use a “tunneled catheter,” in their upper chest area, which causes fewer infections than peritoneal dialysis therapy (Stevens et al., 2009, p. 542-543). All patients in this thesis study had tunneled catheters, of which they referred to across the board as “central lines,” since there were two lines going in and out of the catheter: one to extract the blood, and another to return the clean blood (Stevens et al., 2009). Likewise, all participants also drew their central lines independently, but not all lines were the same, or were connected to the dialyzer.

A major area of study in the literature is the task of understanding the patient's perspective of their care. One issue that was prevalent in this thesis study is in communication with the dialysis care team. Allen, Wainright & Hutchinson note the importance of “concordance between patient and clinician,” especially in “interactions that are associated with technology-driven, efficiency focused care which excludes patient knowledge (2011, p. 133). In the dialysis unit, breakdown of trust seems to occur when there is a breakdown, or the perception of a breakdown of communication between patient and clinician (Allen et al., 2011). In hæmodialysis therapy, and in other patient: clinician scenarios, it is therefore important for the healthcare team to ensure they communicate clearly with the patient, and that the patient communicates clearly with the healthcare professional.

Allen et al. note, “Patients who are unable to trust their clinicians are, of course, less inclined to openly communicate with those clinicians or integrate their medical expertise (2011, p. 133).”⁶ However, they acknowledge this might be because they also “don’t feel trusted as legitimate knowers by the medical professionals” (Allen et al., 2011, p. 133). In

⁶ This trust is built with open communication, and I witnessed this breakdown in the unit when new machines were installed, clinicians experienced difficulty using the machines, and the patients did not understand why the machines were beeping all the time, which usually meant their blood pressure was too high or low. Where the most trusting patient, Cooper, lost hope temporarily was in his second map, which was created shortly after the new machines were introduced, and when he had an infection partially because of the new machine too.

addition, “non-compliance” is “bi-directional” between patients *and* clinicians: it is a valid description for some patients, but not all (Allen et al., 2011, p. 133). The authors ask, “By devaluing chronically-ill patients’ experiential knowledge (by naming them non-compliant), does medical practice inadvertently contribute to what it so commonly refers to as non-compliance?” (Allen et al., 2011, p. 133). This question highlights the importance of reciprocal communication between patients, and staff in the dialysis unit.⁷

Rose Richards chose to address the perspective of the dialysis patient from her own story, in an autoethnography of “Kidney failure, transplantation, and recovery” (2008, p. 1717). Part of her work to write this autoethnography, I think is to relieve her emotion of frustration experienced from her medical doctor. She states, “I remember once being told by a doctor that the transplant operation was going to be painful. I asked him how bad the pain would be. He looked at me blankly, and then repeated that it would be painful” (Richards, 2008, p. 1719). The doctor clearly dismissed her question in this interaction, but Richards’ question was also non-descript.

Later she says, “Had he been through kidney failure himself, he might have been more compassionate about his patients. This could have

⁷ A loss of trust, based on the experiences of patients in my thesis study, might lead the patient to resign from attending to their healthcare, and it is difficult, if not impossible to reverse this pattern.

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augmented his medical expertise" (Richards, 2008, p. 1719). Her claims are extreme, but worth considering. It is not really fair for her to say, "Had he been through kidney failure himself," but her second statement about if he was in that position, that it could have "augmented his medical expertise," seems to be a wish of Richards' more than a known, or possible reality (2008, p. 1719). Say it might be true, that 1 in every 1,000,000 physicians has had kidney failure and a successful transplant so that they could augment their care; it is still a red herring fallacy for Richards to state this, as the chances of any patient experiencing this level of empathetic care is likely nil.

Nevertheless, I appreciate Richards' report, as after sharing her story of kidney failure, she says:

I feel as if I am the girl who lived." You cannot be the same after something like that. My illness is not the only thing that defines me, but there had been so little of me before it started that I find it hard to escape a medicalized view of my life. (Richards, 2008, p. 1721).

When reading her initial breakdown of her experience, I felt it seemed she was saying that her illness defined her, but it makes sense that it did not sociologically define her, as much as it did in all other ways—medically, physically and emotionally—and maybe this is what kept her going? Her autoethnographic story contributes to redefining illness experience from the perspective of the patient.

ILLNESS ADJUSTMENT PATTERNS

Researchers sometimes organize experiences of illness into adjustment types or styles. Radley and Green describe illness as, “an adjustment within the spheres of bodily and social experience, subject to culturally shared beliefs and expectations” (1987, p. 180). In their article, “Illness as adjustment: A methodology and conceptual framework,” four types of illness adjustment styles were developed based on interviews with cardiac patients, to learn about their specific illness behaviours and experiences (Radley & Green, 1987). These illness adjustment types (IATs) include: “accommodation, active-denial, secondary gain, and resignation”; the IATs fit with my study with patients receiving regular hæmodialysis therapy, and are transferrable to many different health scenarios (Radley & Green, 1987, p. 189-190).

Radley and Green challenge the idea of the *Parsonian* ‘sick role’ and found that it is a vague, and over generalized trait that cannot be attributed to all people in the same way (1987). A parallel example of this phenomenon was highlighted in the Globe and Mail newspaper, where immigrant newborn babies labelled underweight in Canadian hospitals are actually healthy by their own national standards (Weeks, Feb. 15. 2012). Many factors, including ethnicity, genetics, culture, economics, and family history are at play in their birth weight. Though birth weight is a good measure of a

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newborn's health, a Canadian newborn often has different measures than a newborn of an immigrant family (Weeks, 2012).

Here, one measure of birth weight has moved Western medicine policy makers to reconsider their evaluation of 'normal' birth weight for future cases of all immigrant newborns. As with newborns, illness experiences and roles are diverse, and depend on individual attitudes and social connections (Radley & Green, 1987). They note:

From the perspective of the healthy person, illness and health confront each other as separate states, the former represented in the outer conditions of social life and the latter expressed in the individual's own 'reserve of health'. When s/he falls ill, the sick person's conduct effects a transformation of these conceptualized states through the re-adjustment of the individual to society. (Radley & Green, 1987, p. 181).

Not everyone will fit into the idea of a sick role, resigning from life to attend to his or her illness. Some will, and they meet the illness adjustment pattern of resignation, but they often begin in other patterns of adjustment first (Radley & Green, 1987). Nevertheless, Radley and Green note in this passage, that some people will express two somewhat overlapping, or parallel types of traits (1987).

They give an example of this overlap in a patient, who has expressed active-denial traits, but in reality, the patient was at a stage in their healing which was perceived as active denial; the IAT was actually accommodation because they came to accepting their illness experience (1987). Though the patient expressed active-denial traits, accommodation can also be noted, to

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help interpret the data from the lens' of perception *and* perspective: the researchers' perception of what the patient expressed: active-denial, and the perspective that the patient actually experiences: accommodation. It can also be dually recorded to account for the witnessed change in the patients' acceptance of their health.

From these IATs, Radley and Green wrote twenty questions to sway a respondent to “accept” or “refuse” a condition of the question (1987, p. 196). After accepting or refusing, the respondent either fit, or had no fit at all with the illness adjustment type. Then, the responses were scored based on the type they fit into, or not, and were organized quantitatively based on “acceptances” or “substitutions” of the prescribed adjustment styles (Radley & Green, 1987, p. 196). This stage would be avoided by qualitative researchers, but it highlights the benefit of this methodology for researchers interested in mixed-methods approaches, which Radley and Green also note (1987).⁸

Maintaining a stable quality of life is the goal of hæmodialysis therapy for older adults with, or at risk of developing end-stage renal disease. Though

⁸ In my own study, I draw on Radley and Green's framework. My goal in locating participant experience of dialysis in terms of “illness adjustment” (Radley & Green, 1987) is not to classify or typify participants' experiences. It is true that in each case of interviews, participants expressed experiences that *fit* into these categories neatly; likewise, all participants *fit* neatly into other categories expressed by Radley and Green (1987) as hybrid adjustment types. Therefore, I cannot say that the participants entirely meet the criteria for these *types* of illness adjustment, but they do express traits and patterns, which Frank calls, “a kaleidoscope pattern” (1995, p. 76).

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older adults with indications of kidney failure might end up with the diagnosis of end-stage renal disease, they should be given equal opportunities for early hæmodialysis therapy, or kidney transplant.

Reciprocal communication between patient and dialysis staff is essential for positive patient health, and breakdown in communication because of a loss of trust with patient care should be worked through as early as possible to prevent patterns of dependence and resignation. If a care provider knows about illness adjustment styles before meeting with patients it might support a greater awareness of patient coping styles and boundaries that impact reciprocal communication in patient: clinician interactions.

This literature review supports doing further research into body mapping practice with people in a health care setting, such as those at Toronto Rehabilitation Institute in the Dialysis unit as a means to address body awareness, communication, and illness adjustment styles.

Chapter 2: Methodology

The research question in this study is, “Does body mapping give geriatric inpatients with ESRD receiving daily hæmodialysis therapy a voice to communicate their sensations, pain and experiences?”

RESEARCH DESIGN

The process for collecting data in this study was structured into two stages: three one-on-one body mapping sessions and one, one-on-one post-session interview each, with each participant. After the participants completed their body mapping sessions, I conducted one, one-on-one private, open-ended, semi-structured interviews with each participant independently to ask about their experience of participation in body mapping. Because of their tight rehabilitation schedules, these interviews always took place a day after the third map, or the afternoon of creating the third map. I planned to conduct the sessions out over four weeks per participant, but this was not possible with the research timeline, and busy participant rehabilitation schedules.

In the in-depth, semi-structured, audiotaped, one-on-one interviews, participants discussed their experiences of body mapping while undergoing hæmodialysis therapy (Appendix B). The interview questions were designed around three core themes: (1) experience of participation in the body

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mapping sessions; (2) perception of what was meaningful about body mapping; and (3) aspects or factors of the process, or environment in the dialysis unit. Each theme was introduced before asking questions to each participant; for example, “Next, we are going to discuss your perception of what was meaningful about body mapping”. Simple probes, such as “why is that?” or “can you say more?” were used to glean more in-depth responses to the questions.

The open-ended quality of the interview questions allowed participants who had a difficult time understanding some of the questions to explore other responses to questions that they were more comfortable with responding to. Data from these interviews and observations was manually transcribed. The data was coded into a set of two core themes, and indexed using the framework approach (Pope and Mays, 2000). The patterns and themes were evaluated in-comparison to existing literature using an interpretive analytical approach (Pope and Mays, 2000).

The benefit to this research is that participants had a chance to express how body mapping has possibly changed their views on using art as a healing, and communication tool for their hæmodialysis treatment. This process gave each participant an opportunity to reflect on how they plan to continue with body mapping on their own, or in the community.

RECRUITMENT

All geriatric rehabilitation participants on unit 6-South at the University Centre of Toronto Rehabilitation Institute were invited to participate in the study if they were receiving regular hæmodialysis therapy.

With the invitation letter, the local Principal Investigator (LPI) at Toronto Rehab approached participants in her circle of care and asked them about their willingness to speak with me about this study. I received the list of participant names to contact for the study from LPI. I secured from the program staff a schedule of their appointments and introduced myself to the participant during a scheduled appointment, discussed the study details, and reviewed the consent form with them. I encouraged participants to discuss the study with family members or friends if they wished; however, all participants wanted to speak right away, likely because of their tight schedules.

I let the participant know that I would be on the unit three days from the day of reviewing informed consent, and would check in with the participant at that time about their decision. This initially seemed possible, but because of the participant schedules again, most participants either invited me for a first body mapping session that afternoon following informed consent signing, or for the next day. I assured the participants that participation was voluntary. The appointments for body mapping and the

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interviews were made a day or a week in advance with the participants. A system of reporting to nurses, and a consultant psychiatrist, was set up in case a participant showed signs of distress (this system was not needed during the study).

Sixteen participants were approached, and seven out of sixteen consented to participation. Two were unable to participate because of their discharge dates, and two withdrew. After body mapping and interviews with the first three participants it became clear that there was a volume and richness of data that, for an MA study, justified ending recruitment.

SAMPLE & RESEARCH PROCEDURES

Five people participated in the study from December 9, 2011 to March 15, 2012. Jean, an 80 year old man; Carmine, a 70 year old woman; Rosa, an 82 year old woman; Cooper, an 80 year old man; and Yana, a 78 year old woman. Jean and Yana withdrew from the study; Jean completed two body maps, but became ill, was transferred to an acute care centre in Toronto, and when he returned to Toronto Rehab, he was not interested in completing the study. Yana completed one body map, but because of a busy rehabilitation schedule, and becoming ill, she withdrew before the start of her second body

mapping session. All participants, except for Yana had end-stage renal disease.

At the first body mapping session, the participants were presented with a blank outline drawing of a body representing the participant, sitting in a dialysis chair on a 9x12” piece of cardstock paper (Figure 1). This was the template that we used for the remaining two body mapping sessions.

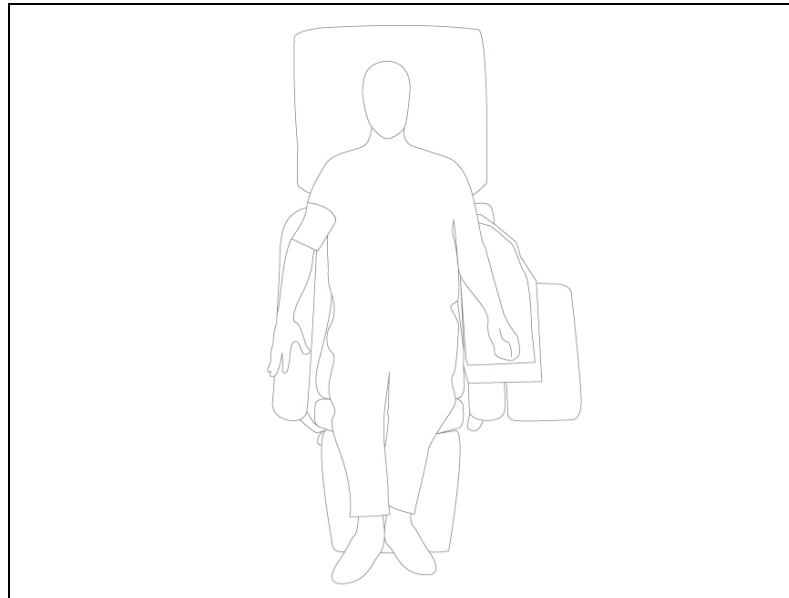


Figure 1: Template for study

A variety of thick, and colourful watercolour pencils were available for the participant to use to draw, or write on the body map. They also used permanent art markers. Participants could also add water to their drawings once complete, but there was not time to do this as most tired after an hour to a forty-five minute session.

Participants could decide what they wished to share on the body map. They were encouraged, but not obligated to explore any sensations (hot, cold, aching, etc), or emotions that they were currently experiencing by drawing, or writing about them on the body map, and on the location on the body map based on where they are experiencing the sensation or emotion the strongest. For example, participants could express their feelings about aging, what it feels like to be ill, losses, and changes in their self-image and life style.

My role was to assist participants with using the pencils and painting, if they chose. I did not evaluate their creative work, nor question participants' decisions about what they chose to draw or write.⁹

I facilitated the three body mapping sessions with an unstructured approach, and developed three themes from the sessions, outlined in the following table:

Table 1: Approaches to Facilitation of Body Mapping Sessions with Hæmodialysis Patients		
Session 1	Session 2	Session 3
Theme 1: Body Mapping: comprehension > Assisting participant with connecting with body: face, arms, legs,	Theme 2: Mapping Body: exploration > Assisting participant with connecting with body: face, arms, legs,	Theme 3: Body Awareness: connection > Indicating (drawing) pain,

⁹ To prepare for the body mapping sessions with this population, I tried body mapping with the same template as the participants (Appendix E).

<p>shoulders, and so forth, by asking about regions “face”, “arms”.</p> <ul style="list-style-type: none"> > Indicating (drawing) pain, sensations with colour, types of lines > Noticing body language of participants (facilitator) > Noticing gender differences: openness, participation, interest, focusing (facilitator) > Challenges: representing ideas/thoughts, sensations, pain, denial of pain: distraction from excess pain, moving away from, or toward symbolic representation 	<p>shoulders and so forth, by asking about regions “face”, “arms”.</p> <ul style="list-style-type: none"> > Indicating (drawing) pain, sensations with colour, types of lines > Naming pain and sensations: verbally, and via writing on map > Numbering pain areas chronologically (one case) > Labelling pain, sensations (“itchy”, “cramps”) 	<p>sensations with colour, types of lines</p> <ul style="list-style-type: none"> > Naming pain and sensations: verbally, and via writing on map > Labelling pain, sensations (“itchy”, “cramps”) > Drawing visualizations of thoughts > Asking participant to think about their body in relation to the room, machine, mind and body.
<p>December 2, 2011; revised March 15, 2012. By Bryn A. Ludlow</p>		

The body mapping sessions took place in the Dialysis Unit on the main floor of Toronto Rehabilitation Institute while participants were receiving treatment. Participants did not mind creating body maps while other participants were in the same open room, as none wanted their curtain closed for privacy when asked. I provided a padded lap desk for participants to draw or paint on so they were comfortable using the materials.

The first theme, “Body mapping: comprehension” involved questions that helped participants learn how to share their experiences on the map. The second theme, “Mapping Body: exploration” involved questions as probes

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that reminded participants about their body regions such as the “arms” or “feet,” and then participants often also explored the mapping process like a world explorer, naming, numbering, indicating, and labelling their pain/sensations. The third theme, “Body Awareness: connection” involved questions that encouraged participants to consider how their body was connected to the room, the dialyzer and how they could represent this experience on the map.

This open thematic approach was designed in-parallel with the themes of the semi-structured interview that followed each body mapping session. These open themes were re-worked across all body mapping sessions until the end of data collection, since there is not an existing guide in the literature for how to approach questions during a body mapping study.

Participation involved a maximum of one hour of participants’ time per week each week for four weeks. The one-on-one interviews took place either in a private room at Toronto Rehab where the LPI was not working or in participants’ room if they had a private room on the unit. In the interviews, all three maps were spread out in front of the patient on a table, from the first to the third map. Participants responded to the interview questions using the maps as a reminder of their experiences during the body mapping sessions.

DATA COLLECTION AND ANALYSIS

Arts-based inquiry and grounded theory approaches are used to discuss the theoretical underpinnings inherent to the research methods. First, however, I offer my own reflection on the key methodological processes involved in this study. These processes are extracted from four qualitative research methods used in the process of data collection:

- Body maps (12 maps)
- Observations and field notes
- Semi-structured interviews (3 interviews)
- My illustrated response to body maps (4 illustrations)

Processes (in italics):

- Body maps: *Visualizing*
- Observations and field notes: *Looking*
- Semi-structured interviews: *Discussing*
- My illustrated response to the body maps: *Witnessing*

“Visualizing, looking, discussing and witnessing” are the methodological processes guiding this study within the scope of arts-based inquiry. However, there is overlap with these principles within each method used; for example, *visualizing* took place in my illustrated response to the body maps, and *looking* likewise took place in all four methods.

GROUNDING THEORY & INTERPRETIVE SOCIAL SCIENCE

This study involved a grounded theory approach to data collection. Charmaz

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notes that a key characteristic of grounded theory is “simultaneous involvement in data collection and analysis stages of research (2003, p. 497).” This characteristic stands out in this study particularly because of the use of two key research methods: interviews and body mapping.

The maps and interview data were compared and analyzed across participants in the time between seeing participants, and therefore each participants’ work informed and built on the next (Charmaz, 2003). Because of the complexities of scheduling mapping sessions and interviews in light of the unfixed nature of dialysis treatment schedules, participant fatigue, cancelled appointments and so on, there was a lot of empty time that I could use for writing and reflecting on the data collected to-date at the hospital.

An unexpected discovery about this research process is that the body mapping sessions turned into mini, informal interviews. Following each body mapping session and interview I took in-depth field notes about the sessions, so I was able to capture some key outcomes from these discussions (Appendix D). I suggest that future research design using body mapping should involve a semi-structured interview script for the body mapping sessions.

It helped to take field notes as a way of debriefing and checking in with myself as a facilitator; at times it was difficult to hear participants’ stories and witness their suffering and challenges with body awareness. Writing reflexive field notes also helped with recall of the body mapping

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sessions with participants. I engaged in reflective painting when data collection was complete, and created drawings of each participant showing how I felt about their work, their stories and experiences they shared, as well as how their illness and sharing in their body maps impacted me as a facilitator/researcher (Appendix F).

The findings were analyzed using the interpretive social science approach, as outlined in Kreuger and Neumann (2006), which they note, is “traced to German sociologist Max Weber (1864-1920) and German philosopher, Wilhem Dilthey (1833-1911) (p.77).” The authors note:

The interpretive approach is the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings to arrive at understandings and interpretations of how people create and maintain their social worlds. (2006, p. 78).

The aim of body mapping is, in-essence, to understand how people give meaning to their experiences in society. Kreuger and Neumann note, “Human action has little inherent meaning. It acquires meaning among people who share a meaning system that permits them to interpret the action as a socially relevant sign or action” (2006, p. 78).

Thus, in body mapping work, the map itself has little meaning other than being a piece of paper with pigment imprinted on the page by each participant in this study. When participants are carefully observed in the body mapping sessions while mapping, field notes are taken, the maps are discussed in a semi-structured, open-ended interview after the series of three

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body maps and interpreted intentionally with questions, then the body map is transformed into a representative object of the participants' experience at the time of creating their body map.

ARTS-BASED INQUIRY

Knowles and Cole note, “Arts-informed research is a mode and form of qualitative research in the social sciences that is influenced by, but not based in, the arts broadly conceived (2008, p. 59).” In this, the key phrase in this quote is “is influenced by,” because many art forms are not based on research, and many artists are not connected to research at all; some are opposed to it. However, this leaves everything else open to be connected to research inquiry.

Sandra Weber's chapter on “Visual images in research” explains how images are used in research (2008). The use of the body mapping method was brought into this study to find out if it would be a good method to respond to the research question. The body maps created by participants in this study work into Weber's set of “visual components” because the maps were created by participants as data for this study (2008, p. 47).

The maps were not given to the participants to read, and the participants did not look at any sample body maps before making their own.

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However, it might be useful to consider these other components in future body mapping work to re-work the approach with the method. Weber wrote ten arguments for the use of visual images in research (2008). In context of this thesis study, #1-7, and #9 will be responded to here:

1. *“Images can be used to capture the ineffable, the hard-to-put-into-words (Weber, 2008, p. 44).”*

Weber quotes Eisner’s “all-at-onceness” (1995) to discuss this component, and in the body maps for this study, participants had the opportunity to share everything at once, but not everyone did, which is okay.

2. *“Images can make us pay attention to things in new ways (Weber, 2008, p. 44).”*

The body maps were created by the participants, but facilitated by me as the researcher, and both of us paid attention in unique ways, given our unique perspectives. Author of “Qualitative Researching,” Jennifer Mason identified the core issues of visual and visible research (2002). In the body mapping sessions, Visual research is what the participants construct; versus visible research is what I observe (Mason, 2002).

Body mapping is both a “visual research method,” and a “visual data product,” because it is a way of doing research, and it produces material—a body map— that can be researched (Mason, 2002, p. 104). This dualistic relation between visible and visual research occurred simultaneously for me as both a facilitator and researcher of the body mapping sessions. It was also

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a similar experience for the participants who understood that they were being researched, and knew that they were producing body maps.

3. *“Images are likely to be memorable (Weber, 2008, p. 45).”*

As participants created their body maps, I watched them create, and can look at some maps now and remember the journey they took when mapping. If they had the opportunity, some participants might likely be able to do the same.

4. *“Images can talk; they can have what Ong (1982) calls, “An ‘Orality’,” a narrative quality or the ability to provoke or reconstruct conversations (Weber, 2008, p. 45).”*

Here, Weber is arguing that “images can provoke or reconstruct conversations” on their own, which I agree with and have found to be true after reviewing the body maps in this study (2008, p. 45). This argument responds to the research question in-part, because it allows for the opening up of voicing thoughts, and concerns participants have, with reference to the body maps.

5. *“Images can enhance empathic understanding and generalizability (Weber, 2008, p. 45).”*

Weber states, “Hearing or seeing or feeling the details of a lived experience, its textures and shapes, helps make the representation trustworthy or believable (2008, p. 45).” The participants’ body maps are records, as mentioned in her third argument above, but as records, they were seen, felt

and heard in the body mapping sessions. As such, themes were generalized across, and in sharing, as a researcher I heard, and listened to the stories empathetically.

6. *“Through metaphor and symbol, artistic images can carry theory elegantly and eloquently (Weber, 2008, p. 45).”*

The body maps in this study had a few consistent symbols, and many metaphors that triggered recognition of patterns seen in theories for analysis.

7. *“Images encourage embodied knowledge (Weber, 2008, p. 46).”*

Weber notes, “Visual methods help researchers keep their own bodies and the bodies of those they study in mind (2008, p.46).” In the dialysis unit with the participants, I was viscerally aware of my body and the participants’ bodies at the same time. This added to the emotional intensity of witnessing the participants in the unit. The realization that the state of my blood is okay was reassuring and held me in the present, which is where I needed to be in the research process. To conceptualize this experience, I drew a storyboard:

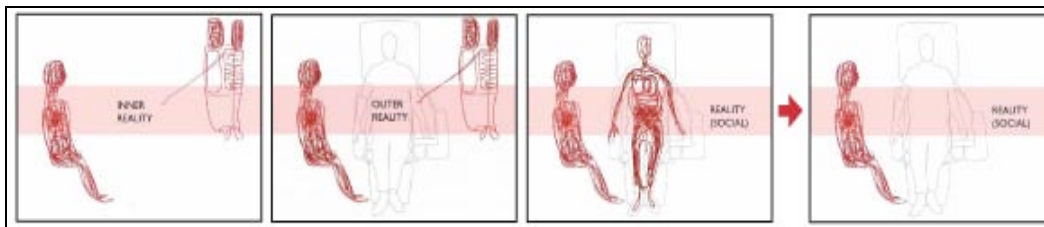


Figure 2: Experience of facilitating body mapping in the dialysis unit

From left to right, the sequence shows a stagnant image representing me

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sitting beside the patient (bottom left of each image). The first image addresses my inner reality as discussed above, with no outline of the patient. With the initial sight of the dialysis machine, I subjectively experienced the participants as disappearing into the machine as their blood was filtered. This was my inner reality, because I did not completely understand the participants' experiences of hæmodialysis.

The second image illustrates an outer reality experience, where objectively, I knew that of course their body does not disappear into the machine. As many participants told me, the machine filters their blood while a mineral solution temporarily replaces the withdrawn blood. The clean blood is brought back in, and the mineral solution is extracted again until their next dialysis appointment when the process is repeated. The third image from the left shows the reality of hæmodialysis therapy—with inner and outer realities merged, which I realized is social (Figure 2). The blood is taken out, cleaned, and put back in again, but the person remains.

Going through this thought process while facilitating the dialysis sessions helped me come to terms with the slightly shocking impact of the presence of the dialysis machines, when I was not used to seeing blood, or understanding that this process helps keep the participants alive.

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9. *“Images can facilitate reflexivity in research design (Weber, 2008, p. 46).”*

Following the stage of data collection, I looked at all of the body maps, and began to reflect on the participants’ experiences holistically across their three maps. After meeting with Yana who withdrew after creating one body map, I remembered how ill she looked and held her image in my mind after seeing her in the unit; I hoped that she would feel well again, not to finish the study, but because she looked so ill; her skin had a green glow. Looking at all of the maps, I created a response to each participant’s work using the watercolour pencils that they used in the body mapping sessions, as well as a black pen for the drawings, similarly to the body outline template on the map (Appendix F).

When creating these reflective responses to their work, I connected to how I truly felt about their work in an objective way. In consultation with art therapist, Suzanne Thomson of the Toronto Art Therapy Institute (TATI), she said that this experience is what art therapists call, “Compassion Fatigue” and she said that it is helpful to build a mindfulness practice into your everyday work to be better prepared to work through the process of hearing difficult stories and witnessing suffering.”

Painting the reflective drawings of the participants acted as a mindfulness practice, but I have since begun to practice meditation everyday,

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to support future work in therapeutic arts. On reflection with images, Weber notes, “By its very nature, artistic expression taps into and reveals aspects of the self and puts us in closer touch with how we really feel and look and act” (2008, p. 46). The participants likely also connected to their true feelings about themselves. This is evident in their portraiture, which tends to open up and face the audience by the time of creating the third map, if they continued to that point in the study (Appendix C). On the contrary, some participants who were less connected to the environment of the dialysis unit, to medical staff, and their bodies drew portraits that were closed, and withdrawn.

Chapter 3: Findings

Two core themes from the research question, “Does body mapping give geriatric inpatients with ESRD receiving daily hæmodialysis therapy a voice to communicate their sensations, pain and experiences?” have emerged from the body maps and interview data in this study. The process of body mapping elicited a theme of “body mapping gives participants a voice to communicate their experiences in the dialysis unit.” This theme is based in communication studies, because the method of body mapping and the stage of reflection in the interviewing elicited a wide range of modes for communication at once, including: drawing, verbalizing, and narration.

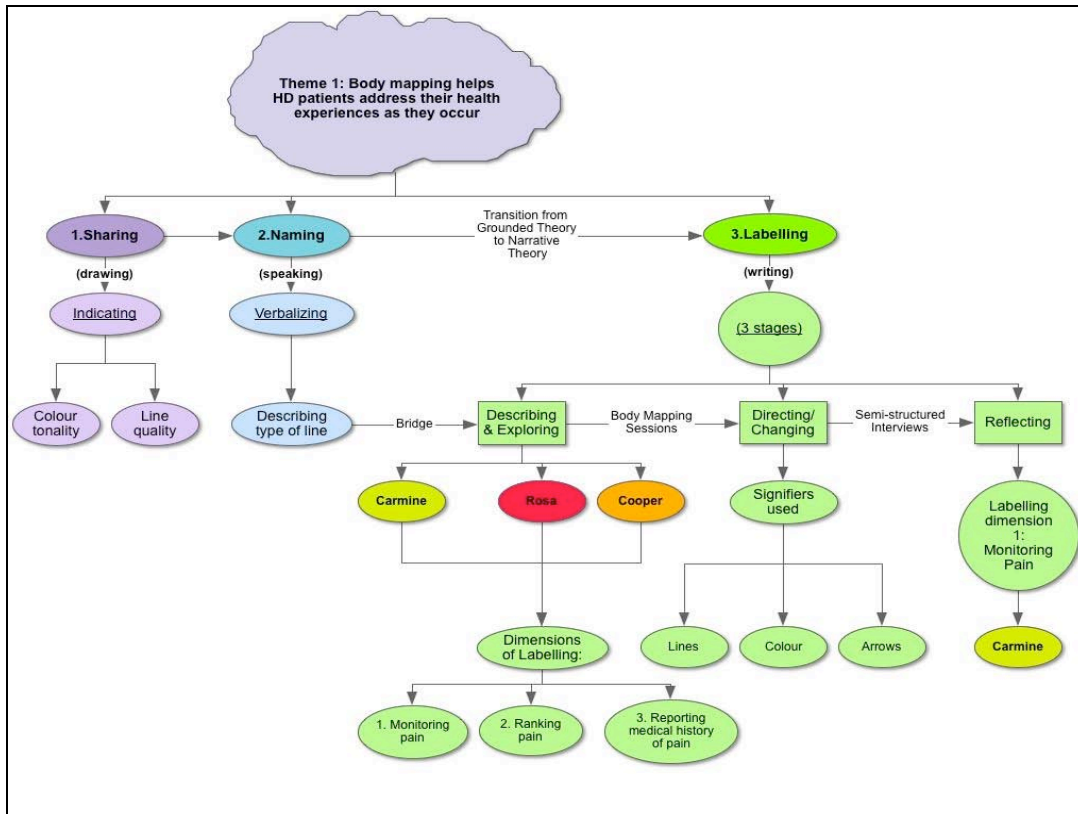


Figure 3: Theme 1 concept map

These modes of communication were seen to flow into each other in three stages of “sharing, naming and labelling” (Figure 3).

BODY MAPPING GIVES PARTICIPANTS A VOICE TO COMMUNICATE THEIR EXPERIENCES IN THE DIALYSIS UNIT.

Sharing through drawing is a stage where a participant first opens up to me as the facilitator/ researcher, and uses the media available—pencil crayons, markers— to produce a form on the body map that represents their thoughts

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about their sensations. Berger (2011) calls this, “probing,” and the participant essentially probes inside their body for the sensation they want to share, then draws it, and it is the “impulse to draw something,” as Berger also notes (2011, p. 150).

Sharing was observed to be an initial stage in this study where a participant used drawing and “indicating” techniques of shading, circling, hashing, and so forth, to express their thought about an experience in and around their bodies (Figure 3: Sharing). The course of indicating extends from the interpretive analytical approach methodology chosen for this thesis study, where once a sensation, thought, or experience is indicated on the paper, the paper map with the drawing on it becomes an extension of the participant’s *shared* experience, and this is therefore where the stage of “sharing” comes from.

The second stage of “naming” occurs when the participant begins to describe through verbalization of their thoughts, the meaning of their drawings (Figure 3: Naming). Across all maps, this stage did not involve writing. It was a moment in the body mapping process where the participant moved from thinking about their pain, sensations, and thoughts, to indicating it on the map with a drawing, questioned what it meant to them, then said (named) what it is in the body mapping session. For example, “*My feet hurt around the toe area and this foot has more severe pain.*”

This stage is significant in body mapping, because it is the only stage where the participants independently gave voice to their experiences: pain, sensations, cramping, based on their drawings in the sharing stage. In the approaches to body mapping chart, this stage also most often occurred in the second series of body mapping, where participants commonly felt a greater urge to explore their sensations using body mapping (Table 1). For some participants, by naming their sensations, they were then inclined to move to labelling their named sensations on the map with text.

In the labelling stage, participants wrote words directly onto their body maps (Figure 3: Labelling). Participants expressed themselves in three unique ways in the “labelling” stage, including: labelling for monitoring pain and cramping, labelling for ranking pain and cramping, and labelling for reporting medical conditions. Each participant mapped about one or more of these three types of labelling. In the approaches to body mapping table, the labelling stage commonly occurred in the third body mapping session; but some participants still labelled their sensations and experiences across all three sessions (Table 1).

Aside from these reports of health experiences, in each session, all participants expressed a social dimension of their experiences as people and inpatients. This result highlights the social dimensions of health expressed with the method of body mapping in the stage of labelling. MacGregor notes,

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“the body mapping exercise demonstrates that bodies are inherently social”
(2009, p. 94). I return to this point in the discussion.

SHARING

Sharing was prevalent in both the body mapping sessions and interviews, but it is experienced and expressed differently with each method. The body mapping consisted of descriptive and exploratory sharing, and the interview consisted of reflective sharing (Figure 3). One significant aspect of this theme is the depth of the participants’ reflective sharing— some shared more than others. Some named their sensations more than sharing stories about their health, and everyday.

In this study, when a participant shared a sensation, they drew it inside, or outside of the body map outline. They consistently drew lines with a jagged edge quality, or smooth, depending on the type of sensation they were expressing; and they moved on to other “indications” of sensations, again, choosing the type of material to use. These were important decisions made in the mapping that allowed the participants to express their sensation as accurately as possible.

For example, Carmine used medium green pencil crayon to indicate her cramps in all three of her maps.

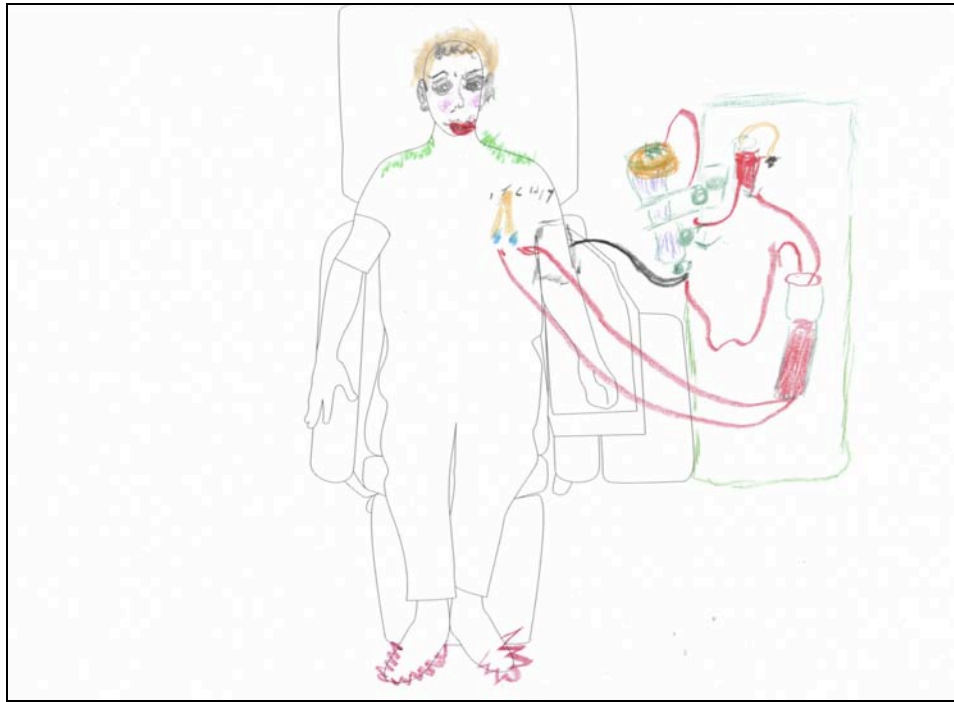


Figure 4: Carmine, body map 1

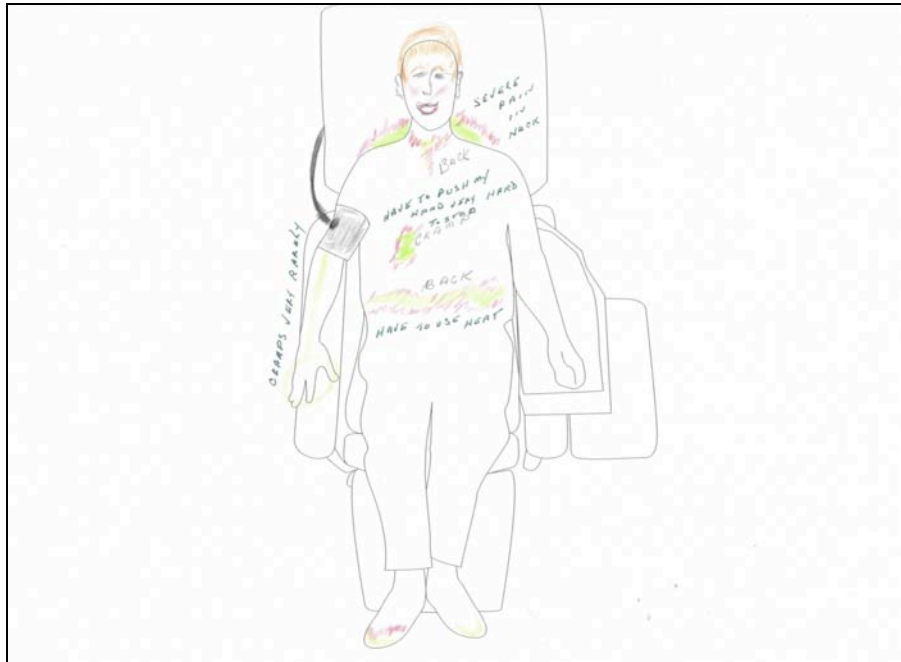


Figure 5: Carmine, body map 2

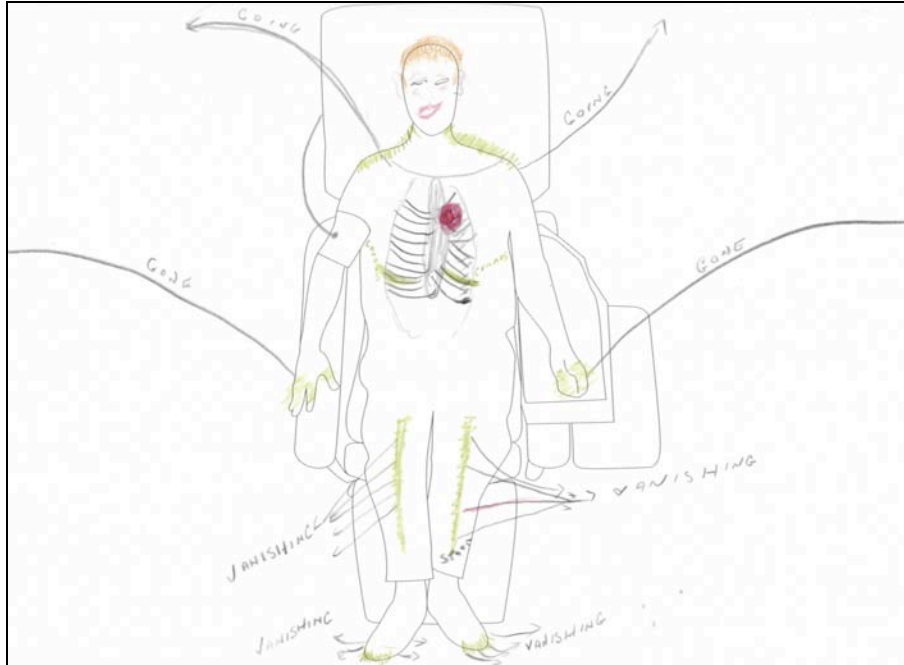


Figure 6: Carmine, body map 3

On her second and third maps, she drew these cramping sensations on her shoulders, lower front right rib, arms, hands, shins and feet (Figure 5 & Figure 6). On her right arm and hand she drew a hard line over her upper arm at the elbow, then released the pressure over her forearm, then added pressure again to darken the colour around her hand. In the body mapping session, after drawing this flowing sensation on her arm, she said that the cramping was not in any particular area of her hand, but it radiated around her hand; it was not as painful on her arm, but hurt more on the upper arm. In this description, she moves from sharing to naming, when she tells me about her cramping sensation.

Naming is a verbalization of the sensation; using the body map, in the body mapping session and in the interview, she spoke out to me: “it hurts here, like this, and why.” Compared to sharing, which is an *indication* of the sensation through drawing it out independently on the body map, naming occurs when the participants speak about their drawings.

NAMING

The verbalization stage of “naming” is the stage where participants gave voice to their experiences, communicating to me as their facilitator with a

specific method (Figure 3: Naming). They would say, for example, “It hurts here, like this,” and some also said, “this is how I cope.” Conceptually, the act of naming a sensation externalizes the thought about the sensation and I, the facilitator then hear this. It is heard and responded to, thus validating the participant’s naming of their sensation, versus them holding it in, possibly worrying about it, or developing other internal emotional responses to it, such as anger about having a sensation that they cannot change.

Naming sometimes also indicates that the participant is asking for help. By naming a sensation, participants are not only saying what they are feeling, but they are also telling me that they have this sensation, they might need me to respond and attend to their concern, especially if it is an unpleasant sensation that the participant identifies as being uncomfortable, or they’re not able to cope with it.

Rosa named her experiences in a very interesting way. She first named the sensation, then she named the emotion associated with the sensation, and this was consistent across her entire interview:

No, I just describe my problem. On the body, you have done already (drawn already) and that’s it. You name it, I got every problem: feet, legs, back, kidney, you name it, I got it. (pause) I don’t feel so proud, I feel depressed. I feel hurt, of course. I feel so depressed, because before, you can cook, you can do things, but the sound (suddenly) your life stop. It’s disappoint; ya, it hurt.

Here, she names her “problems” in her body, and then shares her emotional experiences of feeling depressed, disappointed and hurt. It is the only case

where a participant named their sensation, and then immediately named their emotion.

In contrast, Cooper named his emotional response to his experience, and then deflected by justifying the reason for the cause of his emotional

worry:

Bryn: In the second map, I don't have an image right now, but, I remember you used quite a bit of red, and drew your portrait, and that was the time that you had the infection in your line, there was a new machine, and you didn't look so well.

Cooper: Oh shoot, that was the day of the machine, the new machine. (pause) I wasn't. I admit that day, I wasn't. I was a bit worried, because it was a brand new machine. And I heard them talking, and I knew that the techies were having to learn, it's like anything new, there's bugs in things that you have to learn, and you have to learn how to get around them. Same as your computer, and you have to learn how to use it, and sometimes it's harder than you realize. Anyways, that's good kid. I like it. Okay kid, what else do we got?

This is the only example in the transcript where he shares how he feels—worried— about feeling unwell, and about the new machine, and if the ‘techies’ would be able to use it properly.

Carmine was very open with sharing and naming her pain and sensations. She used the body map to move out her pain by drawing lines with arrows moving off the page (Figure 6). She used a forceful sweeping motion to draw the lines in this third map, which she later said in the interview that it was an “out of body experience.” At the time of her third map, she realized that she had all of this pain, but did not know what to do

with it. In previous sessions, she told me that she does exercises with her hands in physiotherapy where she squeezes her fingers and then releases them quickly. In the third map, when she mentioned that she did not know what to do with the pain, I suggested drawing something coming out of her hands—like her exercise:

Bryn: So, can you describe what you did in this map? (3rd map)

Carmine: Well, I had the plane (slip)...the plane...I had the pain in my hands, in my legs, in my toes, in my arms, shoulders, fingers, and I just put “gone”... lines off the page. Then I put “vanishing” when it was getting less, and I put vanishing, again when it was getting less. On the shoulders, I put, “going”. The pain in my stomach was “cramps”. And in my ribs. It was just coming, like someone sticking a knife in you. (Pause) But then it would go away; I would have to hold onto it really really tight because it..it hurt.

She doesn't discuss how she felt emotionally about the pain as the other participants did, but maybe she felt she didn't need to, and this is okay. It seemed as if she visualized throwing the pain away by drawing it leaving her body, and it was a powerful experience to witness.

LABELLING

The third stage of labelling is a convergent and focused stage, where participants moved from indicating, then verbalizing their sensations, to writing about them on the map. Each participant approached this stage differently, and independently. Across all participants' maps, the labels also

vary. Carmine, Rosa and Cooper approached labelling with three distinct styles, and at different depths. Neither Jean nor Yana labelled on their body maps, but Yana shared her map with the resident doctor as a form of monitoring her pain and cramping. These three styles are divided into three types of labelling: (1) monitoring pain and cramping; (2) ranking pain and cramping (3) reporting medical history and pain/ cramping.

Carmine's experience of the study is the most in-depth, as she labelled her maps during the body mapping sessions, and in the interview; her response is isolated in this section as 'a case narrative'. Her style of labelling fits with the first category of "monitoring pain and cramping" as she was labelling types of pain she was experiencing, and on the locations where she was experiencing it.

Rosa's type of labelling fits best with the category of "ranking pain and cramping", because she began her maps by numbering her areas of pain.

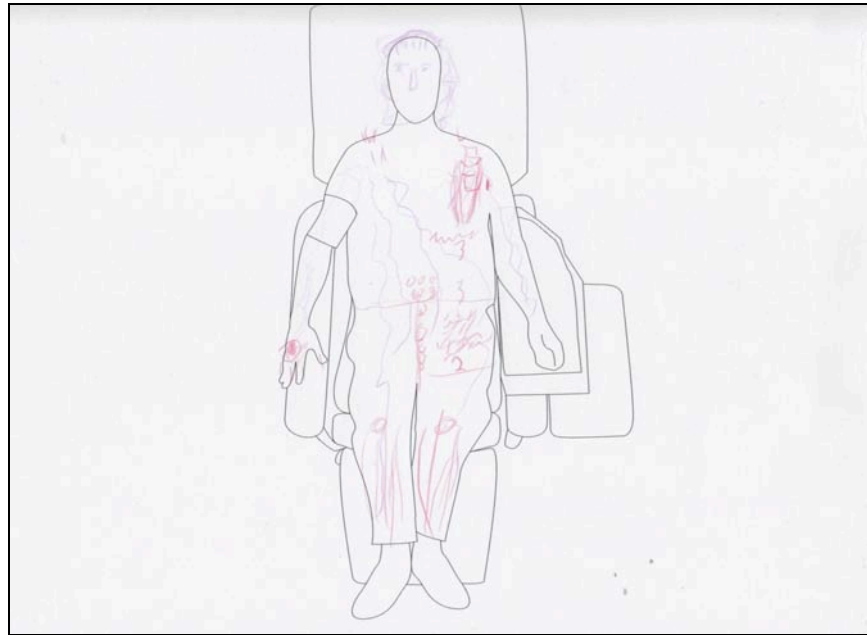


Figure 7: Rosa, body map 1



Figure 8: Rosa, body map 2

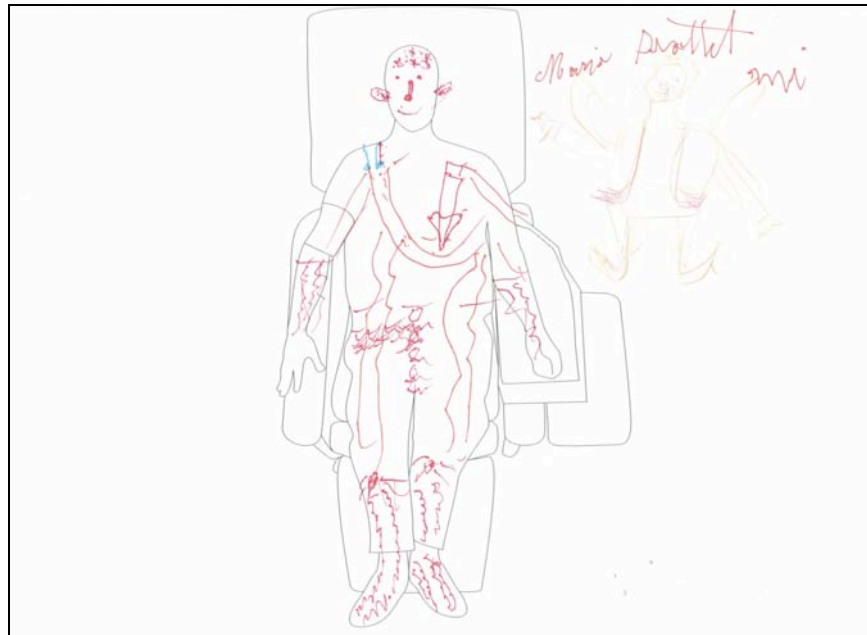


Figure 9: Rosa, body map 3

She called these areas, “problems,” in both the body mapping sessions and interview (Figure 7). After her first map, she stopped numbering her pain, but she drew her “problem” areas in the same sequence as the first map, on the second and third maps.

Cooper’s type of labelling fits with “monitoring pain and cramping”, but matches best with the category of “reporting medical history and pain/cramping.” On his third map, he wrote, “cold,” on his chest area where he felt cold; this is understood as monitoring a sensation (Figure 13). In his second map, at the end of his drawing, where the dialyzer usually sits, he

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wrote a hierarchical list that *reported* his medical history: “No pain; itchy; rash; culture taken; checked by doctor” (Figure 12)

These three different types of labelling expose the narrative patterns participants wanted to communicate in the body mapping sessions and interviews. They discussed these labels on the maps in the interview, and therefore gave voice to their experiences that might not have otherwise been shared.

LABELLING FOR MONITORING PAIN AND CRAMPING

Carmine bridged from naming to labelling in the body mapping, and in reflection in the interview. She also used the label to teach me as the facilitator about what she does on her arm to cope with her pain, “I have to go like this” and she pointed to her lower right side, approximately at the tenth rib area (Figure 5). In her third map, she used labelling to differentiate which sensation she felt was “going, gone, vanishing,” or that she wanted to “stop,” and approached this in a very mindful way. As she visualized her pain disappearing, she drew it leaving her body with lines extending out and off the page, and ranked it with the labels of “going, gone, vanishing and stop” (Figure 6).

In the second and third body mapping sessions with all participants who reached that stage, they shared their maps with the medical staff that were in the dialysis unit at the time, including RNs, technicians, and medical nephrology residents. Yana used her map to monitor her pain and cramping.

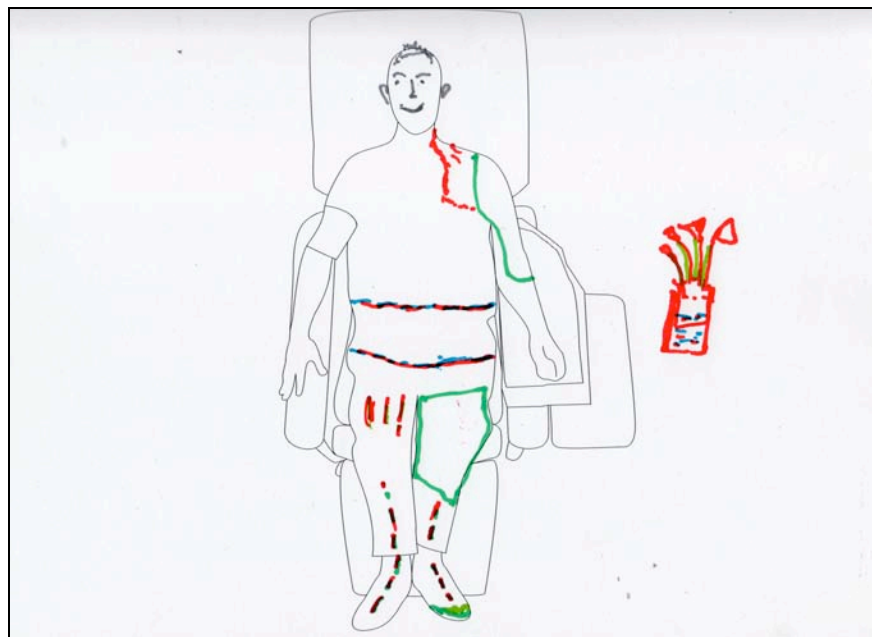


Figure 10: Yana, body map 1

She shared her map with her resident Nephrologist at the end of her body mapping session and right before her scheduled meeting with the resident (Figure 10). The resident found it helpful to look at, as she asked Yana questions about her use of colour and shape on the body map. Yana said that the red areas are where she has intense pain, and green is where there is cramping.

On the first and third maps, Cooper wrote about the social aspects of his health on the maps. On the first map, he labelled his street names, where he raised his family, and where he lives now, which is down the hill from his first home (Figure 11). On his third map, he labelled the cribbage board that he drew on his left side, and wrote “21 holes” for the holes in the board (Figure 13)

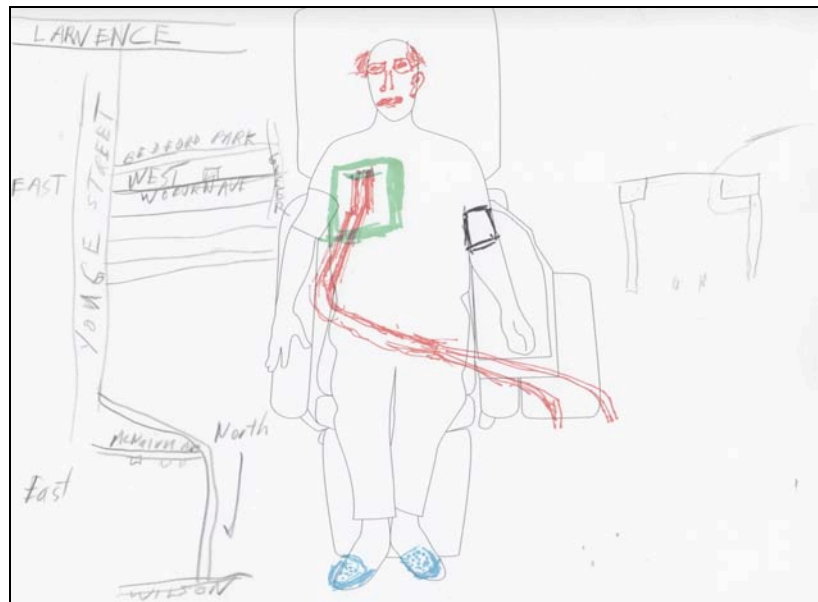


Figure 11: Cooper, body map 1

Though he did not label pain, sensations, or cramping on these two maps, we had a good conversation about the things he drew, which he said makes him “feel good” in the dialysis unit when he gets to talk.

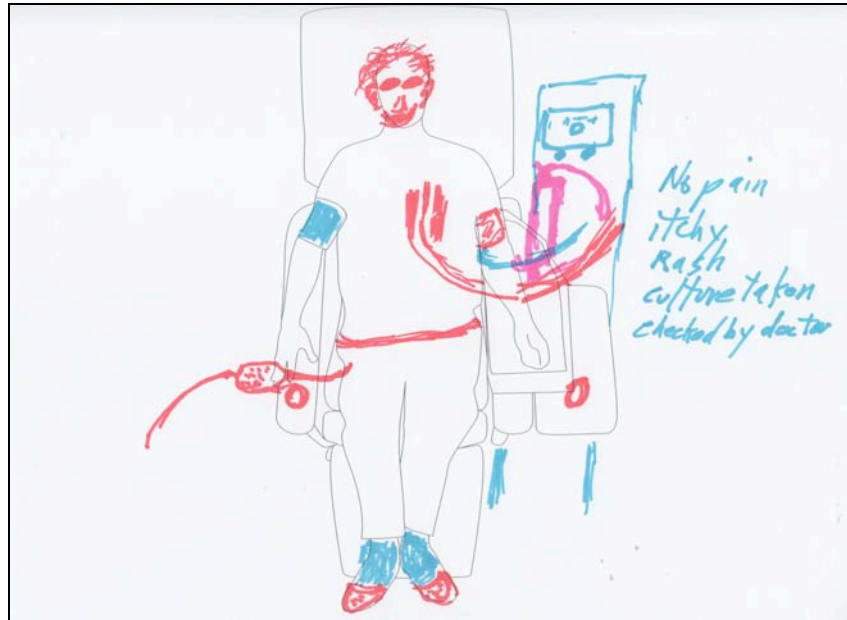


Figure 12: Cooper, body map 2



Figure 13: Cooper, body map 3

LABELLING FOR RANKING PAIN AND CRAMPING

In contrast, Rosa said, “I think about tell you what is my problem. Start from pacemaker.” She labelled her sensations using numbers, in a hierarchy from the worst pain and “problems” to the least (Figure 7). Where Carmine explored the map of her body to locate, name and label her pain, and try to move it out, Rosa “thought about telling me about what (her) problem is”, then numbered it on the map.

This difference might be because of their difference in age (12 years), and health states, but it might also be a very clever way for Rosa to remember what she shared with me, the order of her most severe pain to least, and to make sure that she could share everything. That she wanted to share everything with me suggests a yearning for having a “voice” that she has not had heard by her medical team.¹⁰

LABELLING FOR REPORTING MEDICAL CONDITIONS

Cooper labelled pain and cramping in his second map when he was very sick from an infection in his central line (Figure 12). The body mapping line quality was very heavy compared to his first map, and his drawing looked

¹⁰ Rosa was the only participant who used labelling for ranking pain in this study, but in future development of the body mapping research method, ranking could be suggested as an approach to labelling with numbers.

effortless. He drew his chair and the objects around him. Beside his chair where the dialysis machine is located, he wrote, “No pain; itchy; rash; culture taken; checked by doctor.”

He used blue pencil crayon from the beginning to the end of his third map (Figure 13). At the end of his session, he realized that he felt cold, and wrote this where he felt it at the scoop of his shirt along his collarbone. Perhaps he wrote “cold” and used blue pencil crayon all along because he felt cold all the way through the session? In the interview, he considered the idea of labelling retrospectively, aside from the fact that the interview was a time for reflection. He said, “Oh, uh yea, if I, since we got one like this (the body map sheet), I could’ve written I could’ve put an arrow right here (on the second map) and said, “sometimes itchy.” He averted the question alluding to his experience of naming his sensations and did not elaborate on the labels in his second map.

CASE NARRATIVE

Carmine labelled her sensations with text after the sharing process on all three maps, and gradually increased the amount of labelling after the first, second and third maps. The first label that she used was “itchy” for the central line on the first map (Figure 4). In the body mapping session, she said this was not because of infection as other participants have, but because the circular band aid placed over the central line in her chest gets itchy and she is unable to scratch at it. The second map has much more labelling (Figure 5). She initially used grey pencil in the body mapping session, and then in the interview, she used dark green pen to add more labels to her sensations. With the grey pencil, she indicated that her cramp was on her “back” and she wrote “cramp” on the pain indicated with green and red over her front lower

right rib area. In the interview, she used dark green pen, because it was a different colour than the grey pencil, to add more labels in a reflective way. She wrote, “cramps very rarely” along her right arm. She wrote “Severe pain in neck” which is a label about the type of pain: severe. She wrote, “Have to push my hand very hard to stop” over the lower right rib area “cramp” label in grey. This label is a reflection on how she copes with her pain, by “pushing her hand very hard to stop (the cramp).” Below the cramp drawing and label of “back”, she wrote, “have to use heat,” which is a reflection on how she copes with her cramp in this location.

It is interesting that with the act of labelling, Carmine uses two types of labelling: one in the body mapping sessions where she is sort of “naming-labelling” her cramps, with short descriptors, “cramp”, and “back” for the location of the cramp. The labelling in her interview was reflective; it describes how she copes with her cramping, and the intensity of the cramping (Figure 3). In her third map, she used a third type of labelling—directive labelling— to emphasize the movement of her sensations away from her body, if it “stopped,” is “gone,” “going,” or “vanishing”.

The lines and arrows are extensions of her labels, and she was careful to indicate exactly where the lines were extending from on her body, especially on her legs, where she also added a thin red line on her left mid-shin where it hurt more than other areas. She said in the interview that this process was “an out-of-body experience,” and especially so, when she drew solid, fast strokes extending from her hands and shoulders (Figure 6). She drew the lines around her shins much slower and deliberately to accurately represent the origin of the line, and direction of movement. It was the same

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on her feet; on her right foot, the lines extend from the side of her foot, versus the left foot, where the lines extend from her toes, which are significantly different anatomical areas that caused different sensations in her feet.

Overall, labelling acts like a “sign” for the participants. Not everything is labelled on their body maps, but when it is labelled, it is important and must be attended to, or validated in the body mapping session, even if the participant is actively denying the sensation, or exaggerating their pain. Some participants drew labels after indicating their sensations, and said, “It hurts really badly here, eh”. The “eh” statement is more than a passé Canadian phrase; I received it as a social approach to asking for confirmation that their pain has been witnessed, and the confirmatory act by the facilitator validates their pain so that they can move on to the next label.

Therefore, it is essential to recognize these verbal cues to be able to confirm a witnessing of their pain, or to ask for clarification if it is missed, to establish a rapport with the participant, and to move them toward a higher level, and deeper engagement with the body mapping process. Carmine’s engagement with labelling on her body maps shows how body mapping can be used to change experience during a therapy session.

PARTICIPANTS' USE OF LINE QUALITY, COLOUR, AND TEXT

Across all body maps, the participants intentionally use different line thicknesses to indicate intensity of pain and cramping. This outcome was unexpected; I anticipated much more shading, where the participant turns their pencil or marker on its side and uses a sweeping motion to fill-in sections of their map because of the participants' challenges with hand motility. The only time that shading, outlining, and hatching occurred was with Jean (Figure 14Figure 15) and Yana (Figure 10), who both withdrew from the study. Both participants were very ill, and were not as engaged in communicating with me as their facilitator, or with participating in the body maps as the other participants.

Though it is common to hear colloquially that people will sometimes draw images and symbols that in reflection represent a deep thought or emotion that they did not express verbally when they drew it, in the body mapping, Carmine did intentionally use certain line qualities to represent types of pain. She also did this intentional mapping in a very concentrated way, when she drew the pain along her arm. She did not generalize how her entire arm was feeling, but rather she had less pain at her elbow joint area, versus her hand and shoulder, which hurt more, and therefore were drawn with darker lines. Cooper used a thicker line quality when he was ill from an

infected central line in his second map (Figure 12). This line quality was not intentional, but matches his state of health in that session.

The line quality that the participants used acts like a metaphorical bridge between sharing and naming (Figure 3). For example, in the maps by Carmine, she drew thicker lines on her left shoulder than the right on all three maps. This is the same for other areas on her map, including her hands, where there is more shading on her left side than the right. The cramps on her shins are stronger on the left than the right, where she has indicated a red line on her left shin. In her first map, her left foot has larger zigzags than the right foot. She drew the pain on her left side of her body on the right side of her map on the second map, but it was because the blood pressure cuff was on her left side, but on the right side of the body map (Figure 5). Therefore, the pain indicated on her right foot on the body map is actually on the left foot.

She indicated (sharing) pain on this foot with green, and red. The red marks the intense area of pain, and the green is where it begins. She has a bit of green on her other foot, but it is not as painful as the left foot (drawn on the right side). She says:

Well, the only place I put the red was on my feet on this one (points to first map). It hurt really badly that day. The green is, it's painful, but not as bad as the red.

These line and colour styles construct a bridge between the concepts of sharing and naming, because the participant first shared the pain, then

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indicated how intense it was, then said *why* this line was thicker than the other line on the other side (Figure 3: Theme 1 concept map). If it was intense pain and/ or cramping, Carmine moved to the theme/concept of labelling the sensation. Telling me “why” she drew different styles of lines was the keystone of the bridge, where she shifted from sharing to naming.

This theme finds that body mapping gave participants a voice to express their experiences in a way that felt most comfortable and natural to them in three stages of sharing, naming and labelling. In-contrast to a pain scale often used in physiotherapy, where pain is ranked on a scale of 0 to 10, where 10 is the worst pain, body mapping gives people the opportunity to go deeper into narrative discussion about their health at one time, and, I argue, in the same amount of time as a pain scale interview. Body mapping gives people the opportunity to share (draw), name (speak), and label (write) their pain and sensations on one page. In labelling, participants can go into deeper narrative discussion about monitoring, or ranking pain or cramping, and reporting medical conditions, as well as share their social interests.

Body mapping allows people to identify, control and change their sensations if they try, or as best as they can, if they want to, which I believe cannot be achieved with a numbered pain scale. In this study, some participants were stronger in expressing themselves in one or more stages, but the body mapping and interviews mediated this process so that all

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participants had the opportunity to express a voice for their experiences, versus only having one option to communicate to their medical team, such as speaking.

BODY MAPPING MAKES VISIBLE PARTICIPANTS' ILLNESS ADJUSTMENT PATTERNS AND THEIR LEVELS OF CONNECTION, OR DISCONNECTION IN THE DIALYSIS UNIT.

The theme of “body mapping makes visible participants’ illness adjustment patterns, and their levels of connection, or disconnection in the dialysis unit” arose from the maps and interview data. In the body mapping data, I found that participants can make visible their illness adjustment patterns and compliance behaviours, particularly in the narrative act of labelling (Appendix G). Their connection or disconnection with me as their facilitator-researcher was also evident in their portrait drawings on the maps, which they all independently initiated as a way to say, “here I am” (Appendix C).

The structure of the body mapping and interviews also brought forth in this theme. At the third body mapping session, questions were directed at the participants’ level of body awareness and connection to their dialysis experience and room. The follow-up interview consisted of questions geared toward how participants experience dialysis in the environment of their dialysis unit. Therefore, the combination of the focused questions in the body

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mapping sessions, doing the body mapping in the dialysis unit, and having interview questions geared to understanding participants' connection and disconnection in the dialysis unit resulted in rich data to support analysis in this theme.

ILLNESS ADJUSTMENT PATTERNS

Following interviews with three patients, I noticed that all participants experienced some form of pain, and other sensations such as cramping, but shared it in different ways based on how they regarded their progress, or lack thereof with their dialysis treatment and illness. All participants experienced pain and cramping on different levels, and based on their life experiences, and this influenced how they were able to describe the pain and cramping, or not. Furthermore, when analyzing the interview data, the four types of illness adjustment match with the illness adjustment experiences of the three patients I have seen to-date (Radley & Green, 1987).

My interest in exploring the patterns of illness adjustment stems from the clear patterns expressed in the interview and body mapping data of connection and disconnection in the dialysis unit. These patterns are located in participants' styles of body mapping, based on how participants drew their clothing and body forms and structures in the body map outlines (Appendix

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G). Though illness adjustment cannot be classified in this thesis study from the existing data, the patterns are significant to analyze and present as each participant illustrates one of the four patterns in the body maps and they communicate in styles unique to the illness adjustment patterns that they illustrated in the body maps.

Here I will describe the four patterns of illness adjustment, and how three patients I have seen to date fit with these patterns, with reference to interview data.

1) Radley and Green define the IAT of *accommodation* as:

Indicated by self-monitoring of performance in activities and rate of recovery. Respondents take an active role in coping with their illness while orienting themselves toward the future. Specifically, such responses will indicate that patients (i) seek knowledge about their condition (ii) seek to make modifications in their lives in the future (iii) retain an active and positive engagement in outside interests (iv) accept that adjustments are not merely temporary (v) take an active role in their treatment/recovery. (1987, p. 189).

Carmine is a seventy-year old female who participated in the study shortly before the winter break. She had a rough experience with her health, but seemed resilient and accepting of it: "There's a lot of things I can't do that I'd like to do. But that's what happens." She takes an *active role in her illness*, and was looking forward to going home and reading her books, which is an *outside interest* that she enjoys. She was very aware of the process of Hæmodialysis and its effect on her body:

Well, I was expressing basically how the blood transfers from the body to the machine so it can be uh..all the bad parts of the bacteria can be taken out. One is negative. One is positive. So the red one is positive, and the blue one is negative. Sometimes if they don't work, they change them, or they reverse them, or if it comes out stronger the machine tells them that by making a 'beep-beep-beep' noise.

At one point in her treatment, she must have sought knowledge about the process of hæmodialysis, or listened to the nurses and technicians, rather than ignore them, or do something else, because she knows that when she is on hæmodialysis her blood is filtered and pumped through the machine, along with other 'fluid'. Near the end of the treatment, she said, "the blood is pumped back in, after being filtered and the fluid that was brought in is removed." She notes:

Ya, mapping helps me, I guess, not cramp. I don't know. Or, the machine...you see, what they do is they lower the outtake of fluid, because if they take it out too fast, I'll cramp. So, I say, "I'm cramping," and they'll slow it down. So, I weigh 104.6 (lbs) today.

Before her response above, she said, "today it was really happening (cramping and pain). Yesterday I was alright." I responded, "Yesterday you were doing the mapping" and she noted that mapping helps her, but it might also be because of the machine. That might have been the case the day before when she was doing body mapping, that it helped her to relax. She understands the process of hæmodialysis, she knows the cues of when she will

cramp, she assertively asks for help at the time of cramping, and she is aware of her body weight, which is associated with the fluid outtake level.

2) Radley and Green define the IAT of *secondary gain* as:

Indicated by the person having achieved benefits as a result of the illness. Specifically, secondary gain is expressed by respondents who (i) can spontaneously identify compensations related to their condition; (ii) make use of the time which illness may have thrust upon them; (iii) are able to enjoy being in a dependent relationship to others; (iv) experience benefit from giving up work or social duties as a result of illness; (v) enjoy the relative privacy and decrease in social contact which being ill might necessitate. (1987, p. 190).

Rosa is 82 years old and has been receiving hæmodialysis therapy for about six years. Rosa's secondary gain response might be due in part to her non-compliance behaviours of foregoing participation in group recreation, and communicating differently with different levels of staff about the same issue to gain the same level of support when her preferred care team was unavailable (Allen et al., 2011). In her interview, she transitions to expressing patterns of resignation after describing how she lost trust with her doctor and nurse. She resigns, as she "dwells on her condition," feels "depressed," and feels that her "illness dominates" her life when she repeats the word, "problem" in the interview (Radley & Green, p. 190).

Rosa does not express secondary gain or resignation patterns exclusively, because she does not express how she has "achieved benefits from her illness," does not "identify compensations," and does not express "benefit achieved from loss of work/social life," which are descriptors

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expressed in secondary gain (Radley & Green, 1987, p. 190). Conversely, she does not give in to her illness, as she has ranked her pain on the body maps, and she is not passive to her healthcare; at times, she communicated with an aggressive-assertive tone. Likewise, she was not expressing a sense of helplessness, hopelessness, or worthlessness, and she had a private caregiver with her on the unit at all times.

She did not express feeling psychologically cut-off or isolated, as she always talked about her family, grandchildren, caregiver and her daughter who passed away. Having said this, Rosa has patterns of illness adjustment that meet criteria for both secondary gain and resignation, but not at the same time. The data from Rosa's participation reveals a risky shift to a resignation illness adjustment pattern from secondary gain due in-part to non-compliance behaviour that is associated with a breakdown in communication and loss of trust between her doctors and nursing staff. Her fight to be heard by her medical staff and aggressive-assertive communication style is probably keeping her connected to her health, preventing a loss of connection and leading to complete resignation.

3) Radley and Green define the IAT of *active denial* as:

Indicated by an attitude, which minimizes the condition and maximizes active life through the assertion of good health. Respondents may show a tendency to brief answers, which curtail or avoid discussion of their illness, and make reference to an outlook on life emphasizing the importance of carrying on in the face of adversity. Specifically, active-denial is indicated when individuals (i) try to go on as if the condition or symptoms were not

there (i.e., without making any allowance); (ii) express guilt in relation to social roles which can no longer be fulfilled as previously; (iii) express resentment, bitterness or anger toward their impairment or condition; (iv) try to conceal their illness from others (e.g., when taking medicines); (v) reject the role of 'ill person' either directly or through designating the illness as 'only temporary'. (1987, p. 189-190).

In the interview, Cooper, age 80, frequently attempted to control the interview by responding to the question, then asking me to pose another question. He did not give me a chance to respond to his response, as in a more flexible conversation. A marker for this control is in his use of the word, "okay":

Anyways, that's good kid. I like it. Okay kid, what else do we got?

He said this right after his response to a question I posed about his second body map where he had an infection in his central line and drew it on the body map. He said, "That's good kid. I like it" because he appreciated the question. However, he also had a sarcastic and defensive tone of voice. He started calling me "kid" from here on as a way to feel in control of the interview, as a defense mechanism to prevent me from asking him sensitive questions about his body maps. It sometimes worked, but I also took this defense and control as a cue to respect his boundaries.

When he asked, "What else do we got?" it is a good example of what Radley & Green say, "Respondents may show a tendency to brief answers which curtail or avoid discussion of their illness, and make reference to an outlook on life emphasizing the importance of carrying on in the face of

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adversity (1987, p. 190).” This was a brief response, used to deflect a response from me, and to avoid discussion of his illness because he did not want to elaborate on the intense drawing filled with red and blue—the colours of the in-out lines going to the dialyzer.

4) Radley and Green define the IAT of *resignation* as:

Indicated by the person feeling that the fight against the illness has, if only temporarily, been lost. This may be expressed either through personal feelings of passivity, helplessness or hopelessness, or through interpretations of a diminution of one’s worth as the illness has meant loss of social roles. Specifically, resignation is expressed by respondents who (i) dwell upon their condition; (ii) feel psychologically cut off or isolated from others; (iii) feel hopeless or depressed as a result of their condition; (iv) indicate that they are missing out on social activities in which they previously engaged, or which are enjoyed by other people; (v) express directly the view that the illness has come to dominate their life. (1987, p. 190).

Jean and Yana, though they did not complete the body mapping sessions and did not do a follow-up interview, expressed the adjustment pattern of resignation. Rosa, as mentioned earlier, also expressed a pattern of resignation. Jean (80) completed two body maps. An analysis of his portraits on the maps shows that he was very disconnected to me as a facilitator (Appendix C). He might have found the experience of drawing, and connecting to his body while drawing daunting.

Application of illness adjustment styles is more reliable when combined with interview data, because how people respond to questions—the words they use—are evidence for the adjustment style that matches their response (Radley & Green, 1987). With only body mapping data, it is still

possible to note symptoms of resignation patterns observed in Jean's work, and body mapping might be a new way to explore illness adjustment styles in a visual way.

His body maps do not objectively explore how his body was responding to the experience of hæmodialysis, as the only indication of his dialysis experience in his second map was a drawing of the television overhead, the machine, and central line coming from his chest to the machine (Figure 15). His facial expression is very sad, with a flat expression in the first map, and a frown in the second.



Figure 14: Jean, body map 1

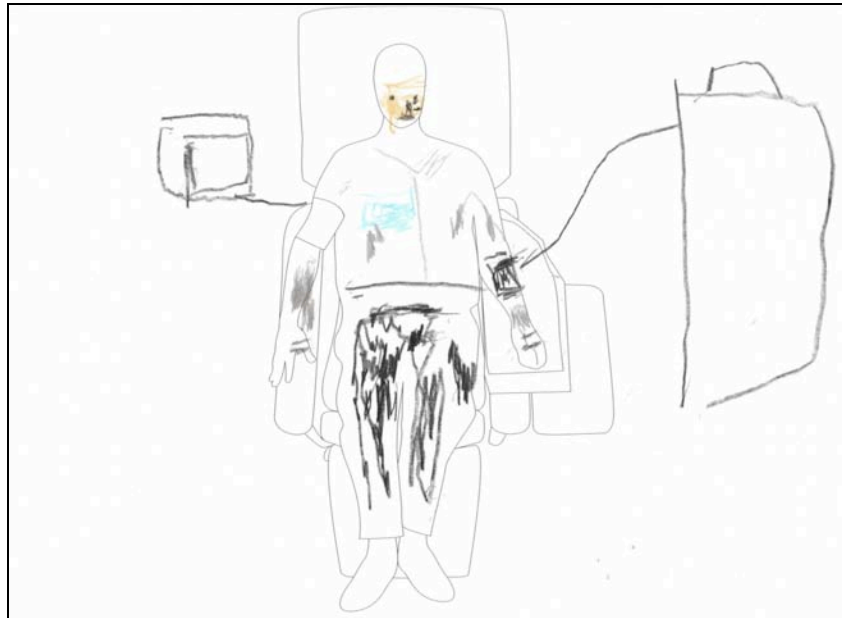


Figure 15: Jean, body map 2

The facial expressions and body positioning in his drawings might reflect his sense of “hopelessness and depression as a result of his illness,” and “dwelling on the condition,” but it is hard to say for certain, as this might be his regular disposition, or because of a concurrent health condition (Radley & Green, 1987, p.190).

Yana was very ill when participating in the study. She also had many appointments, which made it difficult to meet for a body mapping session. When we did meet, she drew a very expressive body map, but spoke of her experience in a resigned way. In the body mapping session, she “expressed directly the view that the illness has come to dominate their life,” and this was likely because of her busy schedule, which it seemed she was partially

made to manage independently when she might not have been able to do that (Radley & Green, 1987, p.190). Her body map is the most geographic in-nature of the maps in the study, as she drew regions of pain and cramping on her body, but these regions, like Jean’s clothing, appear as coverings as she did not explore the deeper sensations that she seemed to be experiencing through witness of her body language.

She drew the vase of flowers in her room that were given to her by her friend, but on close inspection, it appears as if the vase is alive, and there is an expression of a frown in the water; the flowers are wilted (Figure 10). It sits in the place of the dialysis machine, which might indicate a disconnection or withdrawal from her dialysis experience. When I asked her about the vase in the body mapping session she said, “it looks like the flowers are sad.”¹¹

As an interviewer, it was challenging to assess Rosa’s boundaries, if she was resigning from responding to the questions, or if she was asking for attention, as she frequently shifted between these two states. However, it was helpful to know about the adjustment patterns so that I could respect her boundaries and communicate openly with her. For example, she says:

No, I just describe my problem. On the body, you have done already (drawn already) and that’s it. You name it, I got every problem: feet, legs, back, kidney, you name it, I got it. I don’t feel so proud, I feel depressed. I feel hurt,

¹¹ I sensed in this response that she might also have felt sad like the water, but because I did not plan to have a structured interview in the body mapping session, I was hesitant to ask her about this transference; I didn’t want to risk upsetting her while she was receiving hæmodialysis therapy.

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of course. I feel so depressed, because before, you can cook, you can do things, but the sound (suddenly) your life stop. It's disappoint; ya, it hurt.

Here, she said she was depressed, but when I asked her about it, she said she meant that she was sad and not the same person, a resignation pattern. Later, she said:

(Sighs) When you just say "dialys" I'm scared. If tomorrow I walk there, it's impossible. Because with dialys, my legs, square one, square one, square one. If I stay three days, that's fine, but everyday dialys it's hit me, my legs. But the people say, you need it, because if you don't have die.

She is scared of dialysis therapy, and doesn't want it because it makes it hard to walk following therapy, but quotes her medical staff—"the people"—who say that she "needs it to stay alive". Rosa does not say she needs it to stay alive; subconsciously, she knows she needs the dialysis therapy, but is not independently identifying her fears to the staff, suggesting a secondary gain of dependence.

In these examples of illness adjustment styles expressed by participants in the study, it is evident that the illness experiences of the participants fit into the adjustment styles. But it is also clear that each patient could potentially express styles of adjustment from two or all adjustment types at different times in their lives, and based on their illness experiences. However, in one study snapshot such as this, it is hopefully clear from the examples I have given that the experiences of the participants fit into four distinct adjustment patterns, and knowing these patterns supported my

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practice of facilitation of the body mapping and interviews by respecting the participants' boundaries.

PARTICIPANTS' BODIES IN RELATION TO THE DIALYSIS UNIT

In the body maps, two core elements are the participant's body, and the machine. The body maps were analyzed to understand how patients are connected or disconnected to the dialysis unit based on how they draw the machine: its location to their body, and objects or symbols used in-place of the machine.

Jean's first map does not have a machine drawing at all (Figure 14). He sketched his clothing, and drew a yellow circle over my head, which he said symbolized, "nothing," but would not share why he named this as such. As a speculation, it might be because the television was not on at the time, and that was the location of the monitor, with "nothing" on the screen. His second map shows the television, which is over his bed, with a cable line flowing behind his body. His pants are sketched in, and shirt barely drawn. The machine, like the indication of his clothing, floats beside him with no completely closed lines. The tunneled catheter is not connected to his body. Jean's map strongly suggests his disconnection from the dialysis unit.

Carmine's first map shows more detail in her machine than her body, but body mapping was new to her. After drawing the green zigzag lines over her shoulder and the red zigzags on her feet, she moved to draw the machine. She said that when she finished the machine drawing and moved back to thinking about her drawing, the pain on her shoulders was gone. It might have been a sensation of tension that was relieved when drawing the body map. The drawing of the machine in this case sort of looks like a small person, as if it now has her blood and is a part of her, showing her connection to the machine (Figure 4).

Rosa did not draw a machine at all in her maps. She felt very disconnected from the dialysis unit, as she did not have a lot of trust in her medical team. This interpretation arose from her interview where she expresses many qualms with her healthcare:

No the nurse, they do their duty, and that's it. Saturday, Sunday-- I have to say this-- my legs move every day. Of course they feel bad, muscle, nerves, everything, so when not therapy round, and I ask the nurse, you know what they say? "Oh, we don't wanna hurt." Lie back. They gonna lift me. No. So the nurse to me look like when you go to the doctor. Look like the doctor gonna help you, and you believe it. The first thing they wanna know is the health card. To protect them business. Then when you explain the problem, for ten minutes, you know what he say? "For today enough; the rest you tell me tomorrow," and then from that day, I don't believe the doctor either.

When she says, "They do their duty, and that's it," and "so the nurse to me look like when you go to the doctor," she is expressing that she perceives that the nurse, as she perceives that the doctor will help her, but she doesn't want

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to be lifted because it will hurt. It seems as though she prefers care from her therapy team when she says, “When not therapy round.” She believes that the doctor will help, by “his” presence as “the doctor” but he often does not have time, shuts her down by telling her that they will talk about it tomorrow, even after the “problem” has been explained in a standard fifteen minute medical appointment. She therefore resigns and does not believe—loses trust in her primary care person.

After realizing her lost belief in her care team, later in the interview, she realizes that since she cannot walk well (yet) she can only be helped to a certain point at Toronto Rehab and wishes she could go home to heal:

Kidney, my diabetes, my family doctor, my heart doctor, and the other one...? Five? But with five, I end up here. Here help me, but remember, here hope you can walk, ok, they push you, but in my age, 82, with a lot of medication, with dialys, it's too much problem, and they do what they can, and some day, just in my bed, why I gotta stay here? Why I can't be at my house? That's what I prefer.

Though she feels that she has lost trust with her medical team, in the interview, she talks about how she is pushed toward feeling well by her doctor, and she realizes that it will help, that she enjoys exercising more. It might be the case that she has not had a chance to reflect on the benefits of her care before this interview:

If I ask doctor, I check why I have no balance when I walk? He say, “you need to practice”. Practice, I do practice too much here, and I, when I do some exercise, geez, I wanna do more and more and more, because geez your muscles warm, but everyday, it's impossible.

Her first map shows labels of her pain, numbered from 1 to 3 for her heart, sciatica, and spinal pain/ stomach pain—it is not clear based on the location of the 3rd number (Figure 7). Her map looks as if it is bleeding from pain and she forgot to draw her mouth, which, secondary to the eyes, usually shows expression—she is writhing in pain.

In her second map, she said she was feeling tired, and wanted to draw something but didn't know where to start. I suggested drawing a big shape that shows how tired she feels. She chose a blue rectangle that resembles a bed, but it also resembles the shape of the machine, except it is making her feel so tired that it completely takes over her body (Figure 8).

Her third map shows a drawing of her daughter above the location of the dialysis machine; she regards her as an angel as she passed away. She said that she drew her as an angel beside her to protect her while she was at the hospital. The angel drawing is in a similar position as Cooper's first drawing of his veranda and his third drawing of his dialysis nurse, and so maybe Rosa is drawing the angel here subconsciously as representing someone in the dialysis unit. Perhaps she is creating an image of her daughter to protect her, to counter the lack of protection she feels in the unit. In her native language of Italian, she wrote a message to her daughter, just above the drawing of the angel.

Cooper's maps are quite fun and interesting to look at, at first glance, but his mapping is also very different in each session. His first map shows him sitting in the dialysis chair, but facing his street in Toronto (Figure 11). He drew his two houses where he raised his family, and where he lives now. After drawing the streets, he drew his central line and green spill sheet, but the lines look a lot like the drawings of the street. He drew his veranda and side bushes where two cats run through and sit on the veranda to visit him in the location of the dialysis machine. That the central lines and street lines mirror each other, it tentatively suggests connection, but as in the meaning of his name chosen for this study, he *covers* the dialysis machine with the drawing of his veranda.

His second map is very dark and intense. His eyes and mouth are filled in; it looks like he is in a lot of pain, but he only shared having a worry about being ill once in the interview. His dialysis machine is drawn very close to his body, perhaps indicating two things: he knows he needs the machine, and he wants comfort (Figure 12). The machine appears as if it is reaching over to give him a hug. He lists "No pain, itchy, rash, culture taken, checked by doctor" beside the machine as a way of sharing his experience, but these are labels. He skipped the naming stage, and so it might have been hard for him to verbalize his feelings.

Cooper's third map shows a very accurate drawing of the machine, and it was on his right side this time because of the orientation of the room (Figure 13). He was feeling better after experiencing an infection at the time of his second map, and drew himself smiling. As it was his final map, he drew his dialysis nurse beside him. This can be interpreted as him showing his connection to the nurse and sense of support he felt from his care.

This analysis of the maps was challenging to produce because I facilitated the sessions, so knew what the participants created in the sessions as they created it. Nevertheless, as a facilitator, it was valuable to reflect here to study the transitions participants made across the three maps and the differences in connection and disconnection across all maps by participants.

On looking at images in research, Weber notes:

Seeing, being surrounded by the visual, doesn't always or necessarily mean that we *notice* what we see. It is the *paying attention*, the looking and the taking note of what we see that makes images especially important to art, scholarship and research. Indeed the discourse of the academy is all about persuading others to see what we see. But of course, as Berger (1972) asserts, the relation between what we see and what we know is never settled (p. 7). (2008, p. 42).

Many elements of the body maps, such as: the stages of body mapping, participants' use of colour and line, illness adjustment patterns, and noticing common themes were not as clear to me during the sessions, compared to when I analyzed them after, and across each participant's maps. This practice, though oriented in research, might be useful to integrate in the practice of

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body mapping facilitation to ensure that the *findings* of a participants' mapping captures their full experience.

Chapter 4: Discussion & Conclusion

The visual and interpretive response to hæmodialysis therapy for End-Stage Renal Disease using the qualitative health research method of body mapping has addressed the gap of knowledge about patient experience and meaning of illness in a novel way. Seeing the experience of participants on maps of their bodies, and hearing their stories about experience of mapping and hæmodialysis has opened doors to development of further research in this area of body mapping, and in understanding hæmodialysis experience.

DISCUSSION

The two themes in the findings: (1) body mapping gives patients a voice to communicate their experiences in the dialysis unit; and (2) body mapping makes visible participants' illness adjustment patterns and levels of connection, or disconnection in the dialysis unit disclose the experiences of the participants in this study. It is the first time, based on the literature available, that body mapping has been used as a research method with this population, and the findings provide insight to a deeper understanding of the experiences of other participants who are going through the same treatment.

The three stages of sharing, naming and labelling are a significant finding for this method of body mapping, as to-date, no literature in body

mapping research has discussed *how* people express themselves with body mapping. It also allows future work to expand on these stages based on the data and populations that do body mapping.

These themes give evidence for the benefits of body mapping with this population of participants who are receiving regular hæmodialysis therapy for End-Stage Renal Disease, as all participants responded positively to the method, though in unique ways that were largely based on their varying states of health. It also supports continuing body mapping with this population as all participants, except for Jean and Yana expressed a willingness to continue body mapping work.

Given the consistent reference to chronic pain in the literature, my assumption when beginning this study was that participants would express their sensations of pain on the body maps; However, most participants said that they did not have any pain, or were not thinking about it because it was not there at the time of their body mapping session. Some might also have been very good at blocking it out too.

Body mapping gave participants a voice to express a more detailed description of their illness experiences, beyond saying that their bodily sensations were painful. All expressed having *cramping* that was painful at times, but was mostly annoying, likely because they were unable to control their response to the sensation other than by thinking about the time when

the cramping would stop.

In support of the findings of my study for the second theme, “body mapping makes visible participants’ patterns of illness adjustment and levels of connection or disconnection in the dialysis unit,” MacGregor (2009) found that the stories shared on the body maps, “Resonate with an attention to bodiliness: the maps evoke the sense of vulnerability and the loss of control of the corporeal boundaries of the body (p. 93).” The attention to the body inherent to the method of body mapping, as asserted by MacGregor in the quote above—might prevent— from her thoughts, disconnection from the body caused by illness (2009). In a TED talk, Brené Brown, a social work research storyteller realized that “we (people) are here (on the earth) because of connection” (2012).

Findings of her research conclude that people who feel they are disconnected in relationships, with family, friends, doctors, etcetera, have an “excruciating fear of vulnerability because of shame (Brown, 2012).” In body mapping, when a participant pays attention to how their body feels in the boundaries of the body outline and outside (MacGregor, 2009), it might facilitate their attempts to let go of their fear and shame (Brown, 2012). Therefore, body mapping might help people feel more connected to their bodies, and support healthy relationship building.

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In this study, several aspects of participants' narratives echoed Radley & Green's analytic framework of illness adjustment styles (1987). Frank discusses the importance of listening in health care, but notes that listening is challenging because stories often overlap, and many people experience different states of illness simultaneously, or at separate times (Frank, 1995). He calls this a “kaleidoscope pattern” because the stories can be isolated, and looked at comparatively in a study, similarly to looking through a kaleidoscope (1995, p.76).

He states the “kaleidoscope turns much more quickly at the bedside than in print (Frank, 1995, p.76).” Here, he means that in-situ, stories and observations are full, layered and complex, in the case when the kaleidoscope is open; the patient is also sometimes open at the bedside. I say, “sometimes” because some patients have past experiences with health care that influences them to lose trust. This kaleidoscope turning was true during the body mapping sessions, where the participant was speaking about their experiences while drawing and I was watching and witnessing their work, and trying to store their stories for follow-up field notes.

Having a follow-up interview and field notes from the body mapping sessions aided in revealing, and understanding these complex illness narrative patterns, because people do talk during body mapping sessions. The kaleidoscope functions in a similar way as the camera: the person looking

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through the kaleidoscope is in control of how open or closed the kaleidoscope is, and I argue that patients also hold kaleidoscopes at the bedside which is worthy of looking at.

Additionally, Frank outlines that with the three illness narratives, each forms a barrier, which seems to inhibit the possibility of movement between these barriers; my understanding is that the barriers are notches that halt the kaleidoscope along its track, like a vacation timer for a lamp (1995). However, he notes, “Barriers provide possibility for insight (Frank, 1995, p.77).” The insight is an opportunity to analyze the node on the journey of looking, slowing down the turning kaleidoscope even at the bedside (Frank, 1995).

The kaleidoscope is not only a tool for the practitioner, or clinician/ therapist/ researcher, but it can also be used by the person/ client/ participant as a way to look and be objective about their experience— on the other side of the window. Frank notes, “In both listening to others and telling our own stories, we become who we are (1995, p.77).” In an article following his collaboration with Ruth Green in 1987, Radley states:

Since illness adjustment types are not a result of constraints in life, adjustment to chronic illness is ongoing; the ways that people adjust might set-off future problems that could be prevented with this identification. (1989, p. 248).

Though Frank does not elaborate on the kaleidoscope analogy as in-depth as this, it is a strong metaphor for how illness narratives move and shift, from

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both perspectives of patient and caregiver. They can be isolated— not as barriers— but I argue, as windows of which we can look through with a lens of momentary analysis and reflection with the goal of knowing more about a person’s experience.

METHODOLOGICAL REFLECTIONS, AND DIRECTIONS FOR FUTURE RESEARCH

In this section, I reflect on body mapping as a research technology and consider how it can be adapted to include patients who have physical disabilities. I then consider body mapping as a process, reflecting on the various kinds of thinking it prompted among participants. Returning to the literature on body mapping, I discuss the implications of future research; is body mapping a research method or a methodology? I also consider how pre-constructed body outlines, or tracings can partially determine this distinction, or hybrid in body mapping research design.

BODY MAPPING AS A RESEARCH TECHNOLOGY

In the research design stage, it was difficult to assert that doing body mapping would respond to the research question, largely because of the limitations of the population of participants with End-Stage Renal Disease. This population

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has difficulty with vision, motor skills and dexterity because of their renal disease. They are also identified with a high fall risk status, which means that laying on the floor would not be possible.

It is not reliable, nor safe to bring in an artistic method to a health care program simply because it is ‘cool,’ or that the technology is emerging in society (Mason, 2002). Likewise, artistic practice in health care is not a matter of *art for art’s sake*. Artists, or health care professionals wanting to integrate creative arts to their care plans for patients need to strategically decide which type(s) of art making will support the patient/or client in their healing, and which method could turn out to be a waste of time for both groups in the end (Mason, 2002).

The maps were therefore designed to support the research question, as well as to accommodate the needs of the participant population with high fall risk, low vision, low mobility and poor dexterity, using a standardized outline of an androgynous person sitting in a dialysis chair (Figure 1).

To understand how participants experience daily hæmodialysis therapy, I felt it necessary to design a study with three stages of body mapping per participant, but using the same body outline template. The body outline template was used to prevent feelings of inadequacy of body image identified by Tarr & Thomas (2011). The only limitation that some participants identified as challenging was the indication of the blood pressure

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cuff, drawn on the right upper arm, as it was usually on the left arm. But participants acknowledged this, and simply drew it in its correct location on the left side. Cooper's third map was the only time in the body mapping stage when the blood pressure cuff was in the correct location on the right side, because of the different location of the machine. In another study, I recommend leaving out objects attached to the patient's body, as I did with the machine.

BODY MAPPING AS A PROCESS

In response to the methodology, and connected to the findings of this study, are processes of looking and understanding the thought processes involved in body mapping, and discourse between participant and facilitator and vice-versa. Creating a body map with a researcher/ facilitator is a natural sharing process between participant and researcher/ facilitator, and vice-versa. The participant shares by creating the map, the researcher/ facilitator observes, and may ask about why a colour has been chosen, for example. It is a dynamic method, because it supports divergent thinking.¹²

The participant, facilitator and art materials, including the paper body map template are the forum for this divergent thinking process. In

¹² See Appendix E, where I address Solomon's suggestion of body mapping prior to facilitation (2007).

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comparison to an interview, or survey, the body maps and art materials encourage the participant to “do” the work, and thought is optional. Yet, in approximately 60% of the work created by the participants in this study, they did *intentionally think* about their work, and in an intensive way. Carmine and Cooper both expressed that they felt they had to think when body mapping:

*Carmine: Makes you think. It's good to **think** when you're in convalescence...convalescing?*

*Cooper: The only difficulty was, was really, trying to **think** about what to do with the drawing.*

The very subtle difference in both of their responses to the question, “Were there any parts that were not enjoyable? Is that Carmine felt it is “good to think” when convalescing (recovering from illness), whereas Cooper felt that it was “difficult to think about what to do.” Both responses suggest that they appreciated the process, but found it challenging to think while receiving hæmodialysis therapy.

This aspect of “thinking” inspired exploration into the process of divergent thinking. Participants did not scribble in an experiential way on the map about their experiences, hoping to arrive at an unconscious representative symbol of their experience; rather, they deliberately mapped their experiences on the page, as if drawing a map of how to arrive at a

desired destination when travelling, for example. Each participant approached this in a similar way, and at three stages of sharing, naming and labelling. In body mapping and semi-structured interviews, this process of divergent thinking seems to move as a trajectory from the three body maps to the final interview and this idea is best illustrated in the following diagram:

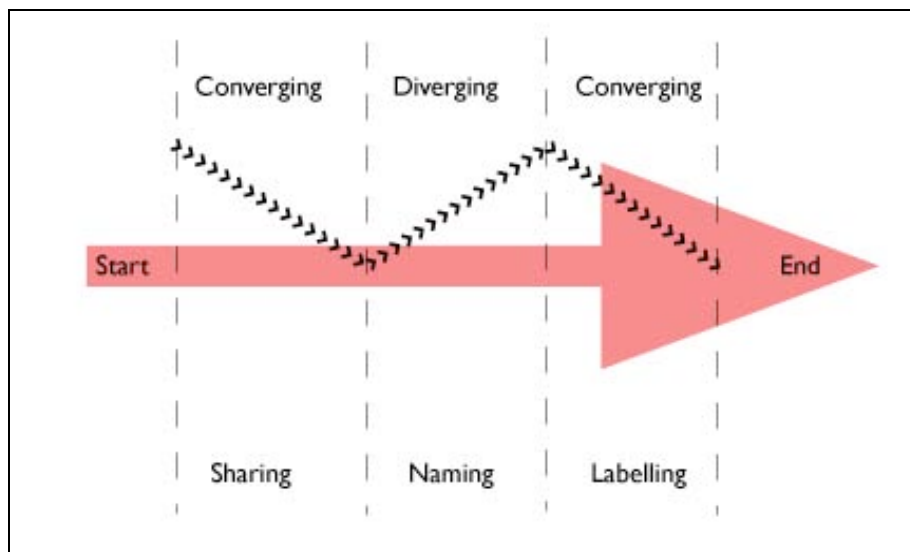


Figure 16: Body mapping process trajectory

The stages of sharing, naming and labelling experienced while body mapping come from higher-level thinking processes involved in looking at the maps, in the body, and knowing about experience; the thought processes converge and diverge at each stage in the theme of “body mapping gives patients a voice to communicate their experiences in the dialysis unit.” To find this voice, the trajectory a patient travels through while creating the maps needs to be

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investigated (**Figure 16**). The stages of “sharing, naming and labelling” are the beginning of this investigation.

At the beginning of the body mapping sessions, participants started with an indication, converging to the sharing stage: they drew on the body map using colour and lines to indicate experiences. Next, they moved to a divergent stage involving naming the drawn sensations, or naming the sensations, then drawing them (**Figure 16**). A final stage involved converging from naming, which is a verbal practice, to labelling through writing and/ or numbering the shared and named sensations on the map. At each point between converging and diverging, I wondered if it was challenging for the participants to shift their thinking in this way, and if so, why? This is an aspect of body mapping as a methodology that merits further study.

Bowker & Leigh star discuss Strauss & Corbin (1988, 1991) who “Posit that bodies and biographies unfold along two intertwined trajectories (the body-biography chain), nestled in a matrix of other structural and interactional conditions” (2000, p. 186). Imagine body mapping as a bicycle chain guard: it partially covers the body-biography chain when the bicycle is rest. In body mapping, participants propel the bicycle, moving the entire chain through the chain cover, revealing their body-biography chain links. If they back-pedal, the chain will fall off, and the bicycle will not move,

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similarly to the case of going back and forth between body to biography. This was realized in my experience of facilitating the body mapping sessions with participants in the dialysis unit.

Body mapping addresses the mind and the body as one, versus separately as a body-biography; with separate inner and outer realities. So, it is true that “bodies and biographies unfold,” but I think body mapping acts to contain these two constructs, like a bicycle chain guard, or in the area of peripersonal space (Bowker & Leigh Star, 2000, p. 186; Blakeslee & Blakeslee, 2008). The body outline—the tracing of skin— is the beginning of the process of unfolding these chains to find the links.

THE FORM OF THE BODY MAP: FUTURE DIRECTIONS

Future directions in body mapping research might address the body tracing stage in body mapping. Three important questions remain from this study and literature review on body mapping: Should a body outline template be used? Should participants trace each other? Should the page be left blank for participants to create their own representational maps without a body tracing? MacCormack and Draper were the only authors to use a body outline template; the bodies were empty, but for the maps of the gynæcological systems (1987). Cornwall was the only researcher to give

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participants open access to the body mapping process (1992). Participants created representational concept sketches about what they thought their gynæcological systems looked like, but the drawings were bodiless; the organs seem to float on the page (1992). To accommodate the needs of participants in my study, I opted for the use of a simple body outline template for all participants to use so that they would be able to participate in the study because of their mobility, vision, and dexterity needs. In all body mapping studies, including this thesis research, all participants independently drew outside of the borders of their body outlines.

All other body mapping work outside of the physiological approach involves a stage in the process where the participants' body is traced and constructed by another person. Tarr and Thomas' work used a machine, a 3D body scanner, to construct the body form, but still some areas were missing, or incompletely captured by the scanner, such as the feet (2011). The outlines in other studies where participants' bodies are traced are outside of the body—also floating, and removed. This begs the question of, “Is a body outline template, or tracing is needed at all?” In each study reviewed in the literature, the researcher chose how to design the study; the staging of the body on the map is therefore a methodological concept.

In this thesis study, it was unknown how body mapping would address experiences of the population of geriatric inpatients with daily

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haemodialysis therapy and end-stage renal disease. Therefore, the body outline template meant that developing themes from the data with grounded theory would be more straightforward than another theoretical approach, because each map could be analyzed accurately across each participant, and within each participant's series of three maps.

If a future study approached body mapping with the goal to understand embodiment, and body awareness, for example, the use of a blank page would entail the use of a different theoretical approach, such as phenomenology to understand bodily experiences of participants (Merleau-Ponty, 1962). Whereas studies using a full body outline might consider other theoretical approaches, such as narrative analysis to learn about the stories that outline the participant's background; the outline, acting as the shadow of the participant's history removed, but also as more than the participant's body. The trajectory of each unique future study will also move in different directions, so it seems that body mapping is more than simply a method in research, it is a way of doing research.

CONCLUSION

Studying the experiences of participants with End-Stage Renal Disease (ESRD) during their hæmodialysis therapy is important work to undertake because of the complicated nature of the health of this population. Results and themes identified in the data and literature contributes to improving the care and experience of participants in this population; evidence built by this study in the body maps and interview data supports continuing body mapping practice with this population. Older adults with end-stage renal disease (ESRD) should not be overlooked, simply because of the fact that there is no alternative treatment such as kidney transplantation that would extend their lives (Stevens et al., 2009). All participants in this study needed daily hæmodialysis therapy to maintain life.

The modality of body mapping gives geriatric hæmodialysis patients with end-stage renal disease an independent voice to express their experiences to their healthcare team. By paying attention, and tuning in to the body with drawing, speech, and writing, participants own their bodies and the inherent power it carries on the journey of life.

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APPENDICES

APPENDIX A: INVITATION LETTER AND INFORMED CONSENT FORM

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APPENDIX A: INVITATION LETTER AND INFORMED
CONSENT FORM

Invitation Letter (printed on Toronto Rehabilitation Institute letterhead)

You are invited to participate in a research study during your stay at Toronto Rehabilitation Institute called, “Body mapping with patients at Toronto Rehabilitation Institute who are receiving hæmodialysis treatment: A qualitative study.” Body mapping is a creative art activity that helps people express thoughts and experiences of illnesses, using art and writing on a ‘map’ of their body.

Your decision to participate or not will not affect your care at the Toronto Rehabilitation Institute, and I will not have any knowledge of who decides to participate or not in the study. Only the student, Bryn Ludlow will know who agrees to participate.

To be eligible for this study, you must be an inpatient of the geriatric unit on 6-South at Toronto Rehabilitation Institute, and be receiving hæmodialysis treatment.

Agreement to be contacted about study details

I agree to allow Bryn Ludlow (student researcher) to provide me with further details about this study.

Yes No

I agree that the student researcher, Bryn Ludlow, can review my care plan to determine if I am eligible for the study.

Yes No

I understand that if I am eligible to participate, I will be approached by the student researcher to discuss the study in more detail (and given an informed consent form), and can decide at that time if I wish to participate or not in the study.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form.

Name of Participant (Printed)

Signature of Participant
Date / / 2012 day / month / year
Name of Researcher (Printed)
Signature of Researcher
Date / / 2012 day / month / year

Informed Consent Form (printed on Toronto Rehabilitation Institute letterhead)

Study title: Body mapping with patients at Toronto Rehabilitation Institute who are receiving hæmodialysis treatment: A qualitative study.

INVITATION

You are invited to participate in a study. The purpose of this study is: To explore body mapping as a way of expressing body sensations, and emotions for patients who are receiving hæmodialysis treatment.

WHAT'S INVOLVED?

As a participant, you will be asked to participate in:
3 “body mapping” sessions for 1 hour at a time;
A one-on-one interview for up to 1 hour at the end of the program, discussing your experiences of creating a series of three body maps.

WHAT IS BODY MAPPING?

Body mapping is a creative art activity, designed by Andrea Cornwall in 1992, and then taken-up by Jane Solomon in 2002. Body maps help people express thoughts and experiences of illnesses, using art and writing on a ‘map’ of their body.

PROCEDURES INVOLVED IN THE RESEARCH

What will happen during the study?

Your body mapping sessions will take place in the dialysis unit on the main floor of Toronto Rehabilitation Institute while you are receiving treatment. If you choose, you may have a curtain pulled so that your body mapping

session is private. I will provide a padded lap desk for you to draw or paint on.

Our one-on-one interviews will take place in a private room at Toronto Rehab. In the interviews, I will ask you about what was like for you to participate in the body mapping, what you might have gained from it, anything that was uncomfortable or that you didn't like, and about barriers to positive creative arts activity.

At each body mapping session, you will be presented with a blank outline drawing of a body, representing you, sitting in a dialysis chair. A variety of colourful watercolour pencils will be available for you to use to draw, or write on the body map. You can also add water to your drawings once complete. The watercolour pencils are odourless, and not irritating. They will wash out, and will not stain your clothing. You can decide what you wish to share on the body map. You are encouraged, but not obligated to explore any sensations (hot, cold, etc), or emotions that you are currently experiencing by drawing, or writing about them on the body map, and on the location on the body map based on where you are experiencing the sensation or emotion the strongest.

My role is to assist you with using the pencils, and with painting, if you so choose. I will not evaluate your creative work, nor will I ask questions about your decisions about what you have chosen to draw or write. If you have any questions about mixing colour, I can assist with this.

Your total participation will involve a maximum of 1 hour of your time per week, for 4 weeks (4 total sessions).

POTENTIAL HARMS, RISKS OR DISCOMFORTS

Are there any risks to doing the study?

The risks involved in participating in this study are minimal. You may feel a slight increase in stress if you choose to draw or write about sensitive topics. At any time, you may wish to take a short break from drawing, and this is fine.

In the one-on-one interview, you do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can withdraw (stop taking part) at any time from any part of the study, including the body mapping workshops. I describe below the steps I am taking to protect your privacy.

POTENTIAL BENEFITS : Are there any benefits to doing this study?

Some patients have used body maps to communicate with people in their lives (including health providers) about their experiences and feelings; sometimes in these cases others come to understand the patient's experience more fully. You are not required to share your body maps with

anyone, but you can if you wish. You are welcome to keep your original body map, and with your permission, I will also keep a copy.

CONFIDENTIALITY : Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me will know whether you participated unless you choose to tell them. Interview data collected during this study will be stored on my computer using only a number to identify each participant. This computer will have a password to protect the data.

The one-on-one interviews will be recorded on my laptop computer, which is password protected using a password from Toronto Rehab that only I will have access to. Audio from the interview will be transcribed within 48 hours of the interview, and then the audio will be destroyed from the password-protected laptop. Transcripts of interview data will be kept for two years after the study is complete.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any part of the study. You may decide to withdraw from this study at any time, or to request withdrawal of your data, and you may do so without any penalty or loss of benefits to which you are entitled.

LEGALLY REQUIRED DISCLOSURE

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information that you share with me in the body mapping sessions, and/or the interviews including: suspected child abuse of a minor under age 16, intent to self-harm, or abuse by a health professional. If legal authorities request the information you have provided, I may be required to reveal it.

PARTICIPATION AND WITHDRAWAL: What if I change my mind about being in the study?

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your continuing access to services at Toronto Rehabilitation Institute.

INFORMATION ABOUT THE STUDY RESULTS

How do I find out what was learned in this study?

The results of this study may be published in reports, professional and scholarly journals, my thesis document, and/or presentations to conferences. In any publication, the data will be presented anonymously. I expect to have this study completed by approximately April 31, 2012. If you would like a brief summary of the results, please let me know how you would like it sent to you.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have questions or need more information about the study itself, please contact me at:

Bryn A. Ludlow BFA MA (Cand., 2012)
Department of Health, Aging & Society
Kenneth Taylor Hall, Room 214
McMaster University, Hamilton, Ontario, Canada
E-mail: ludlowba@mcmaster.ca

If you have questions about your rights as a research participant, or about any ethical issues relating to this study, you can contact the Chair of the Research Ethics Board at (416) 597-3422 x3081. This study has also been reviewed by the Hamilton Health Sciences/ Faculty of Health Sciences (McMaster University) Research Ethics Board and received ethics clearance.

CONSENT

1. I agree that the student researcher, Bryn Ludlow, can review my care schedule to determine when I am available to meet for my body mapping sessions.

Yes

No

2. I agree that the one-on-one interview can be audio recorded.

Yes

No

3. I agree to the sharing of my body map(s) with the researcher and understand that they will potentially be shown at conferences, and/or published in the researcher's thesis document. My name, or any identifying information will not appear on my body map artwork, unless I decide to share it.

Yes

No

I have read the information presented in the information letter about a study being conducted by the researchers named above.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Name of Participant (Printed)
Signature of Participant
Date / / 2012 day / month / year
Name of Researcher (Printed)
Signature of Researcher
Date / / 2012 day / month / year

APPENDIX B: SEMI-STRUCTURED OPEN-ENDED INTERVIEW
SCRIPT

"Body mapping with geriatric inpatients receiving
hæmodialysis treatment for end-stage renal disease at
Toronto Rehabilitation Institute: A qualitative study."

Research Study Semi-structured Interview Script

2012

Guidelines to follow when interviewing research
participants

INTRODUCTION TO INTERVIEW

Hello _____, I am going to interview you on your
experience of participation in the creative art
practice of body mapping-- your perception of what was
meaningful about it, and aspects or factors of the
program/ the process/ the environment. You may ask me
to repeat, or clarify the questions at any time, and
you are encouraged to share your thoughts on the
experience as openly as possible.

[Review consent form, ask if participant has any
questions, answer questions, ensure comfortable to
proceed].

EXPERIENCE OF PARTICIPATION

(Potential questions of open-ended interview)

1. Can you tell me what it was like for you to take
part in the body mapping sessions?
 - Can you say more about that?
 - What did you enjoy about it/ What about that was
enjoyable for you?
 - Were there parts that were not enjoyable, or
difficult in some way? Why did that feel awkward etc?
[following on participant's comments]

2. What were you expressing in this artwork?
 - In the body maps that you made, were you trying to express anything in-particular, or were you experimenting?
 - tell me more...
3. What medium (pencil crayon/ or watercolour painting) of art did you prefer?
 - What about this medium appealed to you? Texture/ Colour etc.
 - What was the least appealing, and why?
4. Did you share your body map with anyone else?
 - Might you have wanted to, or was it more of a personal activity?

**PERCEPTION OF WHAT WAS MEANINGFUL ABOUT
BODY MAPPING**

5. What aspect of *body mapping* did you find most meaningful? Why? [probe for understanding what about it was meaningful]
6. Is there anything about being in hospital, or being on dialysis, that makes you more, or less likely to want to participate in this sort of program?
7. Some people have said that body mapping helps express things about illness and treatment that are not easily expressed. Was this the case for you, or not really? Can you say more?
8. Have you created art like this in the past?
 - If so, in what context (work, school, leisure etc.)?
 - similarities and differences to this experience?

ASPECTS OR FACTORS OF THE PROCESS/THE ENVIRONMENT

9. Did you enjoy working alone on your body maps after brief exercise instruction, with the instructor, or a bit of both?
 - Why?
10. What other aspects of the environment or what people did, made participation in body mapping easier

or more difficult

- Describe...

11. Some people are happy to have the body mapping end here. Do you have an interest in continuing with body mapping, or creative arts, or not really?

- Tell me more...

- If you would want to continue, what might support that?

- What might get in the way, or be a barrier?

CONCLUSION OF INTERVIEW

We are now finished the interview.

Thank you for sharing your thoughts, ideas and/ or concerns with me. Is there anything else you would like to add?

Please know that this interview is confidential and data will be recorded using your participant ID number for research purposes.

Thank you for your time and participation in this research study at Toronto Rehabilitation Institute.

APPENDIX C: BODY MAPPING PORTRAIT ANALYSIS

After seeing the second participant for body mapping, Carmine, I was intrigued at how she drew her portraits, in-comparison to how the first participant, Jean drew his portraits. Therefore, I collected all of the portraits together on one page for an analysis (Figure 17). When data collection was complete, all twelve maps show very different and distinct changes in facial expression illustrations. In this analysis, I focus on an analysis of the facial expression directions—where the faces are looking— in-relation to me as the body mapping facilitator.

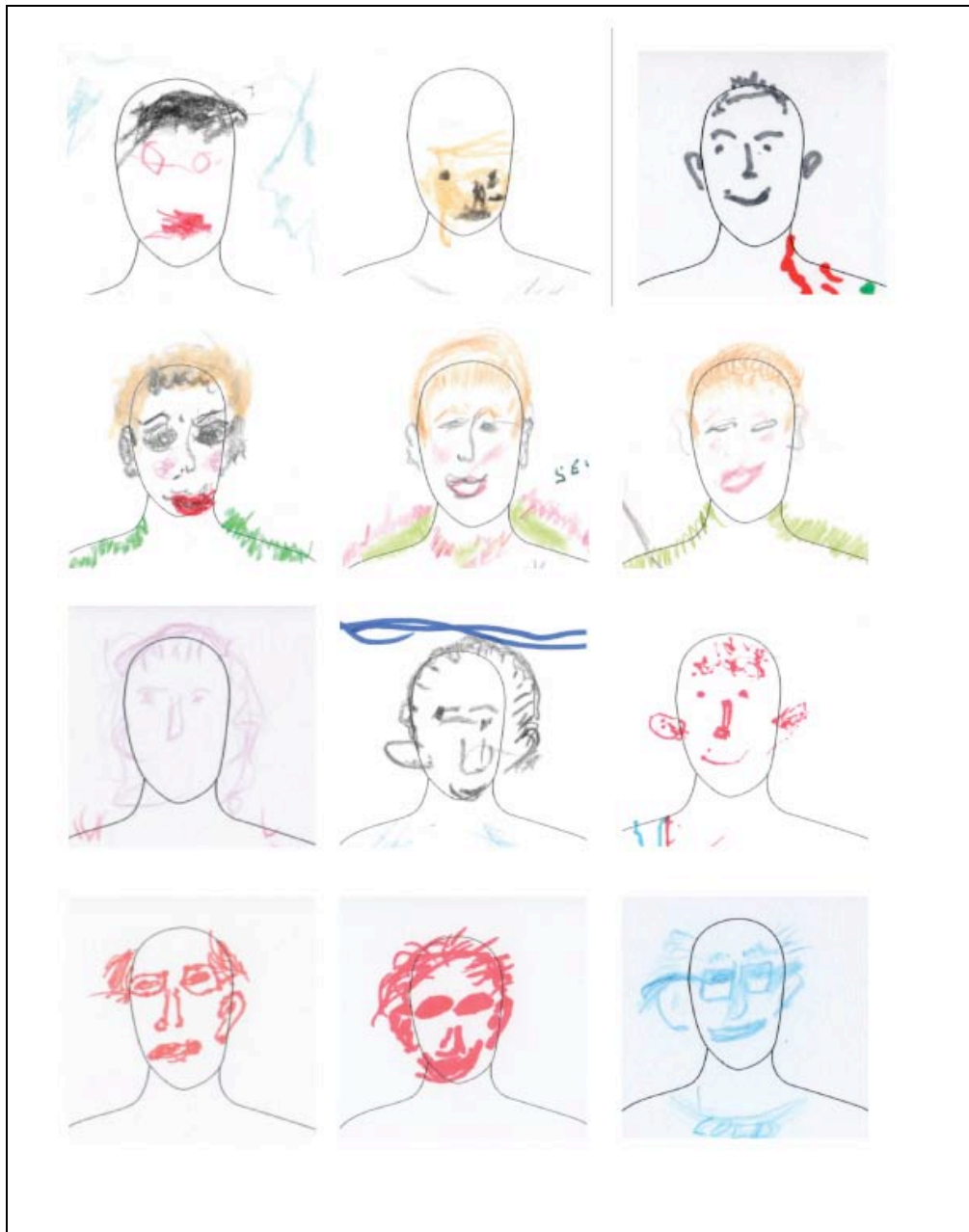


Figure 17: Isolated portrait drawings from body maps

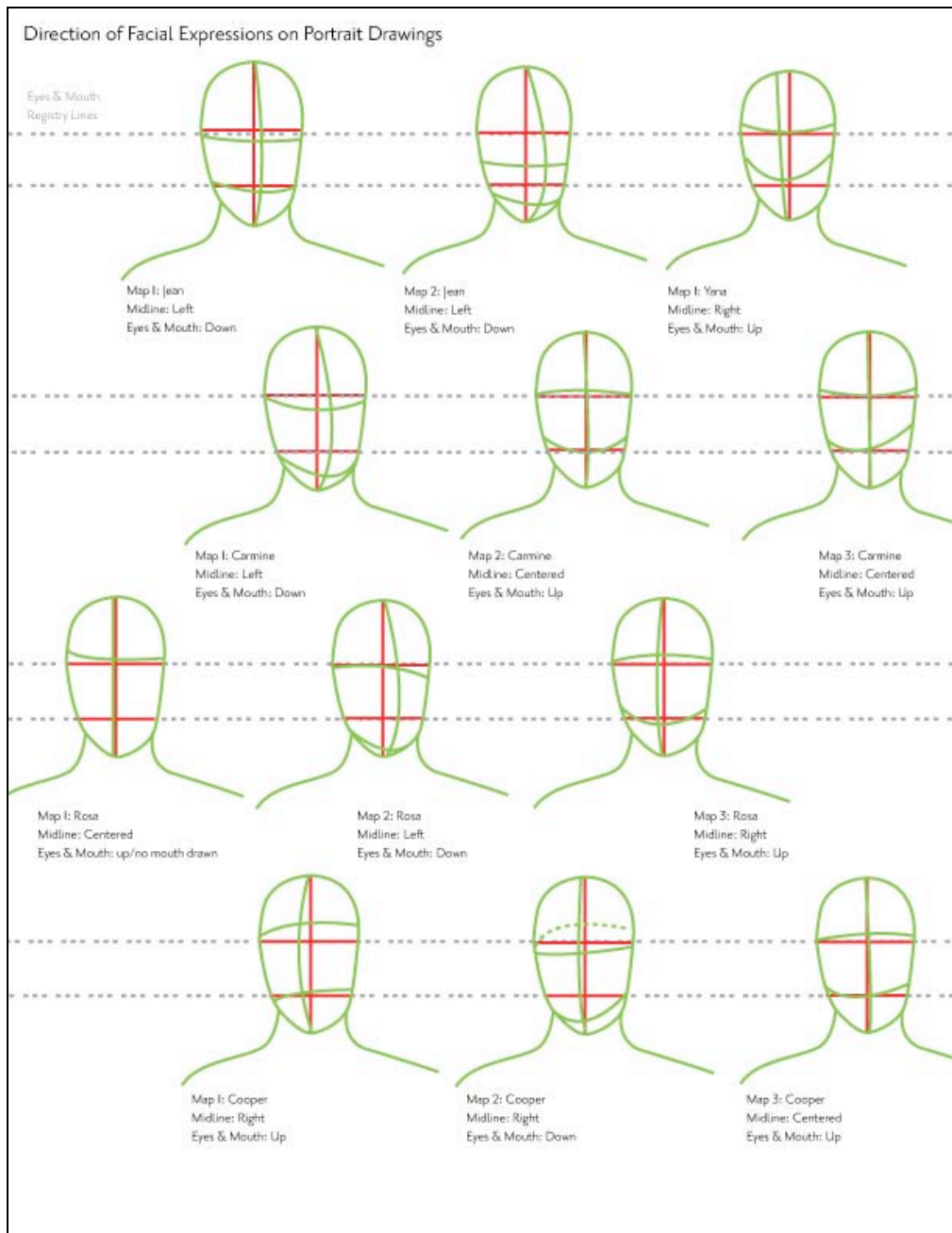


Figure 18: Direction of facial expressions on portrait drawings

In doing this, I drew conclusions about how engaged the participants were during the body mapping sessions; and how this changed by improving,

staying relatively the same, or withdrawing from body mapping, and from me as the facilitator/ researcher.

Many factors influence how the participants express themselves, including their state of health at the body mapping session: how tired, or how much energy they have, and how engaged they are with the study: how focused they were on the task of body mapping, and working with me as their facilitator. It is difficult to assess state of health from a single follow-up interview, and also from three portraits, so the most consistent, and accurate approach to assessing the meaning of the portraits on the body maps is to look at how engaged the participants were, by considering if they were facing me and held a positive expression, or not.

The goal of this approach to understanding participant engagement with body mapping is not to evaluate their creation of their body maps, but rather to draw conclusions about how their portraits matched, or did not fit with how they expressed their sensations on the rest of their body maps. In addition, how they described their experiences of body mapping in the follow-up interview. It is also an important and significant finding in this study that the participants independently gave identity to their maps by drawing their portraits. At a glance, the faces look at, and turn away from the side that I sat on when facilitating the body maps, and so I wondered why

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this happened, as it happened naturally in-person when observing the participant creating their maps?

Using the computer design program, “Adobe Illustrator CS4” I drew green directional lines on the participants’ faces from their forehead to their chin, along their noses, and through the eyes and mouths to show the directions of their faces in the portrait drawings (Figure 18). When the portrait drawings are removed, it is still clear to see the direction of the faces with only these lines, and makes it easier to focus on the actual direction of the face, without the extra drawn elements interfering. This analytical approach was created from the common urban practice of ‘bill folding’ to make the portrait on a bank note appear as if it is sad and happy. For example, when a five-dollar Canadian bill is folded with two creases between the eyes and down to the corners of the mouth, it makes Sir Wilfred Laurier’s face appear as if it is smiling and frowning when the bill is tilted up and down.

After this process of analysis, the theme I noticed across the maps is that the facial expressions change across the three maps, and these changes relate to their engagement with me as a facilitator, and to their body mapping work. But, it is still difficult to draw conclusions based on this observation of some maps, to find out which participant was most engaged, which one withdrew, and to conclude why some participants had little change in facial

expression. Then there is the subjective understanding of these middle-range participants (Carmin and Rosa) who's expressions were down, then up, then down, or up, then down, then up again (Figure 18). This does not mean that these participants did not change their level of engagement in the mapping process. Rather, their second or third map, can be assessed on it's own to conclude how well they were engaged in the process, as the other two maps might have been vague, and not as clear.

Finally, Yana and Jean's maps were incomplete, since they withdrew from the study. It is difficult to say whether Yana would have become more, or less engaged in the mapping process for her second and third maps. Her expression in this single map does not accurately reflect how she was feeling in her body, but this is consistent across all other maps, where the portrait does not completely fit with their expression of body awareness.

I think it is accurate to infer that Jean's third map would have also been drawn with a withdrawn expression, given that his first and second maps are drawn with these expressions; however, in his third map, he might have been feeling really good that day, and might have had more energy to be engaged in the body mapping process. Yet, it is still unknown if he would have drawn his portrait as facing the facilitator, and with his eyes and mouth facing up; it is also unknown if this would have also connected to how he expressed his sensations in the rest of his body, or not. This is similar to the

expressions drawn in Yana, and Carmine’s maps, where their portraits represent how much fun they were having in the process of mapping, versus how they were feeling in their bodies.

After drawing the directional lines, the directions were categorized using two terms for each portrait: one term to describe the direction of focus away from the midline, to the left, center, or right sides. The other term to describe the direction of focus away from the eye and mouth lines together: up, down or middle.

Table 2: Direction of facial expressions				
	Midline	Right	Centered	Left
Eye & Mouth				
Up		***	***	+
Down		*	+	*****
Middle		—	*	—
No portraits in two positions: Up + left, and down + centered.				
* = Position — = Not possible + = No data				

After this stage, all portraits were categorized into the various combinations of ‘eye and mouth to midline directions’. Out of twelve portraits, none had ‘centered and down’ expressions, and no expressions faced ‘left and up’; these sets are indicated with a ‘+’ symbol (Table 2). Four portraits faced left and down, three portraits faced centered and up, three faced right and up, one

faced right and down, and one faced centered and middle. With these categories, it is physically impossible for a participant to indicate their portrait as facing right and middle, or left and middle as both sets are based on the midline direction. This variance is indicated with an em-dash symbol (—). For example, a participant can turn to the right or left, but not to the middle at the same time.

Following the recording of directions of the portraits, the six categories were coded based on how the face of the participant was turned away from me as their facilitator. This process is guided by the core question of, “If a participant is facing the facilitator in their portrait drawing, are they more engaged in the therapeutic process of body mapping, than a participant who draws their portrait facing away from the facilitation side? When doing body mapping, I observed that participants who were more withdrawn than others faced away from me, and also drew their portraits facing away from me on the maps. However, it has been challenging to generalize in the same way with other participants’ expressions and drawings, so having this coding system works quite well to describe their expressions in the portraits.

Table 3: Coding legend
Up= +1
Down= -1
Middle= 0
Right= +1
Centered = 0

Left= -1

“Up” and “Right” combinations are given a high score of +1, because the participant is smiling and facing me (Table 3). In contrast, “Down and Left” arrangements are given low scores of -1, as the participant is not facing me, and is looking down, suggesting a state of withdrawal. Centered and middle arrangements are given a neutral score of ‘0’ because when a participant faces forward to the viewer of the body map, they are simultaneously facing away from me, and facing forward. This implies the participant has a greater sense of independence, and acceptance of their bodies and self. It might indicate an increase in trust with me in the therapeutic arts relationship. These scores were added together to determine if, and how their expression changed over the creation of the three body maps.

Table 4: List of participant scores
Jean
Map 1: left & down (-2)
Map 2: left & down (-2)
<u>Total: -4</u>
Carmine
Map 1: left & down (-2)
Map 2: centered & up (+1)
Map 3: centered & up (+1)
<u>Total: 0</u>
Rosa
Map 1: centered & middle (0)
Map 2: left & down (-2)

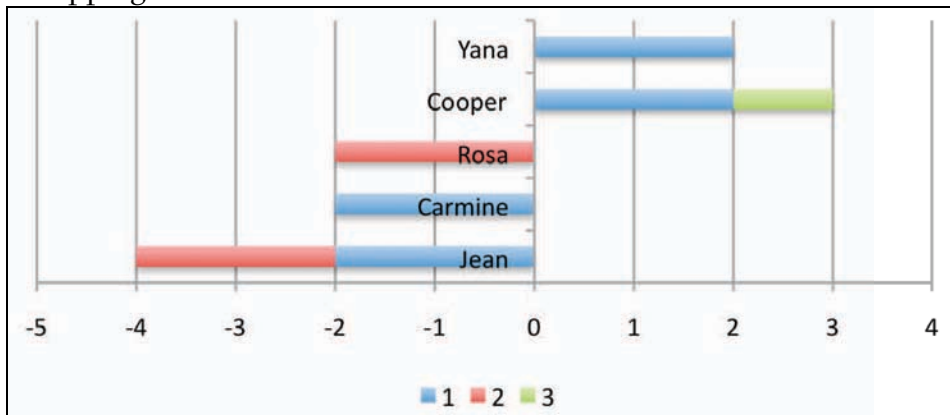
Map 3: right & up (+2)
<u>Total: 0</u>
Cooper
Map 1: right & up (+2)
Map 2: right & down (+1(3)/-1=2)
Map 3: centered & up (0/+1=1)
<u>Total: +3</u>
Yana
Map 1: right & up (+2)
<u>Total: +2</u>
*All participants' scores begin at '0', and each map is added together to achieve a final score.

The eyes and mouth were given a total score, and the midline direction was given a score, and added together to determine the score for that expression drawn on the body map. The reason for this is because of the fact that the eyes and mouth often face in a different direction than the midline in the portraits created by these participants, and sometimes the results end up cancelling each other out, as seen in the case of Carmine and Rosa's maps. The resultant neutral value is just as important for analysis, as is the extremely negative, or positive value of -4 for Jean, or +3 for Cooper (Table 4).

After scoring each portrait, this data was gathered into an excel worksheet, and added together to determine the participants' final states of facial expression change. Carmine's changes were the most consistent in her second and third maps with +1 each, and Rosa had the most withdrawn facial expressions, beginning with a neutral expression, then a negative drop

at -2, and finishing with a positive increase to +2, which moved her back to the neutral position of zero.

Table 5: Changes of expression across the body mapping sessions



This data was translated to a bar chart, showing the changes in expression in each map (Table 5). Where the participant has dropped their score, for example, in Rosa’s maps, she started at 0, moved down to -2, then up +2, the bars are overlapping, so the colours cannot be seen for each portrait, but can be understood in-comparison to the data (Table 4).

Some people do not like eye contact, and so the participants might not have looked at me for this reason, but might have felt okay with the body mapping process. However, this begs the questions of, “why did they feel uncomfortable with eye contact? If they do feel comfortable with eye contact, but did not look at me as their facilitator, does this support a discussion about how engaged they were with me as their facilitator, and the body mapping process? If they expressed a shy or coy expression, could this suggest

a gradual increase in engagement with me, and with the body mapping process?

The changes in body mapping across all maps improved by a rate of approximately 40% overall, which might suggest an improved confidence in facilitation of the body mapping sessions by me as their facilitator, which was projected onto the participants near the end of the study. But, in the second and third maps, all participants except for Jean and Yana showed the medical staff their body maps, and so this suggests that since their expressions changed positively in these maps, they were also happy with their work. Cooper and Carmine both had a very positive outlook on life in- general, and toward their goals of improving their health, whereas Rosa expressed how she has many health “problems”.

The participants made deliberate lines for their eyes, mouths and nose to communicate how they were feeling in those moments in the body mapping sessions, so it is a snapshot in time of their experiences. But, where a participant drew a frown, as in Jean’s second map, it was certainly his intention to draw his mouth, nose and eyes in this way, versus drawing a smile (Figure 17). The intentionality of all participants’ facial expression drawings is worthy of analysis. From observation, all participants checked in with themselves before drawing their expressions. Carmine actually moved her second map side to side with her hands and said, “How are you feeling

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today?” She also paused before drawing her expression, as did Jean, Cooper and Yana. It was less obvious about how intentional Rosa was when drawing her portraits, than it was automatic for her, as she would get right into drawing the expression. At the end of each mapping session, she made reflective comments about her expressions, such as, “I look depressed,” (in her first map) or, “I look happy,” (in her third map).

APPENDIX D: FIELD NOTES

Participant: Jean

Date: November 4, 2011

Time: 9:20-9:50am

Began colouring his pants with black pencil. The area that he coloured represented his pants being filled-in with black. He didn't want to fill-in the entire area. Body language suggested he was tired. He also had trouble seeing, so this might have been why. He didn't know what else to draw. I suggested to draw the stripes on his golf shirt. He liked that idea and quickly drew the stripes. He also drew the collar.

Next, he drew his hair. He was comfortable with the supplies and looked more comfortable to try drawing. He drew in his glasses—they are red. He also drew in his mouth.

He continued to draw his mouth, but asked what else to draw as he didn't know what to draw. I suggested to colour in the dialysis chair, to try

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and connect him to his body more and think about naming emotions, thoughts, pain.

He said he did not have any pain. It felt like “nothing.” PT said he feels “nothing” while on HD; used to go for longer times during the week. I said, “Okay, if you feel nothing, what would that look like?” He said, “A circle”. I said, “Great, what colour would you like to use?” With no hesitation, he said, “Yellow.” I gave him a light yellow to begin with, but he couldn’t see it, and so I noticed he became a bit frustrated, so asked him if “he wanted to use a darker yellow?” He said “Sure.” He continued to draw the circle, and closed it using the darker yellow. He didn’t want to draw the dialysis machine beside him. Was this because it felt like “nothing”? He didn’t want to draw any sensations, or emotions because he said he didn’t have any. It could be socio-cultural guarding; he is married, and maybe in this role he does not show his feelings? He agreed that the yellow circle looks like a sun when I said this.

Preliminary Analysis

His body map looks lonely; didn’t ask him about this as it might have made him upset. He looked tired and because it was the first BM, I thought it might be too much to ask by probing more on his emotions.

The drawing of his face and the yellow circle were the most impressive to me; he also tried to shade in the chair, but became tired. The

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drawing of his face made the body map turn into a representation of him as the patient. It looks like him, and he took initiative to draw his glasses with red and mouth with red.

The drawing of the yellow circle is very intriguing. It was the last item that he drew. He made the effort to make it seen, by using a darker value of yellow. He closed the circle as best as he could. He didn't fill in the circle, leaving it open. He drew the circle on the right side, just beside me, outside of his body. He agreed that it looked like a sun, but didn't say "yes, it is a sun," because it represents the feeling of "nothing."

What does the feeling of nothing feel like? What emotion? Could I use an emotion chart?

November 9, 2011

Appointment scheduled for 8:30am, but patient was transferred to a Hospital in the GTA.

BM-1-Rosa

January 13 2012

Patient began drawing her heart. She said, don't laugh at me, I'll do my best.

This meant that she would try her best at drawing the heart and in the right place. She drew the heart with a red pencil crayon, just under her left shoulder, over her breast area. The heart is in the mid- chest area, but

many people grow up learning that is on the left side, not knowing that it really is only left of midline. Maybe if she had a heart attack, she had left arm pain and remembered this so drew it?

She talked about a thing on her heart that she should draw, and so I asked if it is a pacemaker? She said I'll draw it. I said it was a circle shape right? She's not it's actually a square. She said I have a lot of bad wrong with my heart. She said it's called chronic heart failure and she has two tubes on each side of the heart to keep it moving. She drew the tubes.

Next, she thought it would be useful to number her pain areas, so she numbered as one. She seemed to have a sense of urgency inside of her to list every pain area by drawing numbering the places. She might not have had an opportunity to share this with anyone other than medical staff.

The second pain area is her right hip and upper thigh. She described the pain as fire. She asked if she could write fire and I encouraged her to do whatever she wanted. She chose drawing because she was tired and did not want to write beyond numbering. She drew zig-zagging lines to represent fire. She said the pain moves down her leg and she can't walk if it locks. She said "sciata" asked if she meant sciatica? She said yes that's it. I responded, "oh yes, that's painful."

The third pain area she drew is her gall bladder. She began by describing that she has pain under her great chest area, above her lower

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abdominal area --- she pointed to it and held it with her hands. I then realized she was talking about her gall bladder because she also said that she had stones. She on the left side though, where her stomach would be. At the same time as talking about her gallstones she began talking about her diabetes, therefore that she drew her gall bladder where her pancreas is, she might have been subconsciously communicating her understanding of her pancreas. She might have also been confused by the body outline and where to indicate her pain. She also said that of course the kidneys are not good. She labeled this as number three. She didn't draw them because she didn't know how.

Next, she drew little circles where her spine is --- lumbar to sacral. She drew a line across her body and down the middle --- she drew the midline before drawing her heart. This helped her figure out where the spine is on her body. She said the doctor told me that the sponge (the intervertebral discs) are not there anymore.

After this pain area, she labeled her right hand with the ball of pain and swelling fingers over it. She said that it is called gout. The pain fills her entire hand and she said that she couldn't move her fingers very well.

After this, she labeled pain radiating down her legs. She kneecap in circles, and lines going down to your ankles showing the pain. She said that it happens when she is on dialysis and her facial expression suggested that pain is very bad, and she scrunched up her cheeks.

She began, she checkmarks on her shoulders indicating that they are okay. At the end of the session, she labeled all of her painful areas and all in red pencil crayon. I asked her what makes her feel happy? She said I have a lot of pain and sadness. She said my husband died, and then my daughter too. I am very sorry to hear that. I was feeling down, I asked to use a different color --- I chose magenta, which is similar to red. This way, it does not diminish her thoughts about pain, but will be different from using red. This which is similar to that of systematic desensitization. I asked her to draw her blood flow in her body as a way to reconnect with her body. She became excited by this, and changed expression to a more active focusing. She drew blood flow like things are on the right side where she had no pain indicators, and down her legs, then her arms.

She didn't know what else to draw after this, so I suggested to draw her face/portrait. She drew her eyes as small dots, then her nose as a sort of trapezoid shape, which is a pretty accurate representation. She drew two lines for her eyebrows, then her hair. She said that she used to have long hair, and so she drew long hair; it looked curly, so I asked her she used to have curly hair? She said yes and I told her that I also have curly hair, as a way to relate to her, and also make her feel comfortable. She drew her eyes and nose, but not her mouth. I didn't ask her to draw it though because I wanted to ask her about it in the post-interview. I also thought it is interesting, for many

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reasons: first, because it suggests that either she didn't want to speak, or that she was drawing, so the artwork speaks for her, or that she doesn't usually have a metaphorical voice in the hospital, usually agreeing to medical staff, or that she didn't know what to draw on her own and was listening to my prompts and thinking versus speaking, that she simply forgot to draw the mouth.

BM 1- Cooper

Jan. 26-9-10am

Began to draw his portrait, then the lines coming from his chest. Very bubbly, said that he has no paint, nly feels good, a bit anxious that the line will get infected. After saying that, he moved his finger around and around on his chest in a circle—a coping mechanism for his anxiety. His portrait made both of us laugh. He said that he doesn't have hair to draw. He drew his shoes—blue—the dots are the vent holes in his sneakers. The BP cuff is on the wrong side for him, so he drew it on the left. The lines are facing the ground.

He started to share a story about his house. He drew his nice veranda, big. He feeds the neighbourhood stray cats; buys the dry food for them. Buys the good stuff. One cat, “Conrad” because it is a black cat, (Conrad Black) only has one leg, and he told me the story of Conrad who crawls through the hedge with his three legs and jumps up onto his veranda pillar to eat, then go.

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Then he drew his streets in his neighbourhood. He drew Lawrence Avenue, then Yonge Street North. He drew his house where he grew up, on Woburn Avenue, then he talked about his wife who had Lymphoma and died from that, leaving his three teenage children to raise on his own. He was an accountant and learned how to do computing. His daughter got a job with the Federal government after her Masters degree. Someone read her thesis. His middle son Charlie worked at Pickering Nuclear and was very good at Math. He became an alcoholic, and transferred to Toronto Hydro where he is now. His youngest son David is in education work, I believe (can't remember). After his wife passed, he began seeing Sandra at his job in accounting, who he is with now. She visits him at Toronto Rehab.

Next, he drew his house with Sandra on McNairn Dr. Below Yonge St. He is a very social, content patient/person, and drawing outside of his body is good—a good sign. Suggests he is very connected to his resources, which he said that he is.

I asked him about his veranda being in the place of the dialysis machine. He said, “Yes, it's in-front of the dialysis machine. I see that.” With a sigh, and a pause. Is he scared of the word, “dialysis” as other patients are too?...

BM 2- Cooper

Feb. 9, 2012

In this map, he began to discuss the fact that he has an infection in his line and had it swabbed, culture taken. He has a rash, but it is incredibly itchy but he can't scratch it.

He drew the lines, inflamed and red. He looks unwell, with a yellow complexion compared to the last session. But he said he is okay and wants to stay positive. He drew his portrait next using red, because he did not want to stop writing and drawing. He drew his eyes solid and red. He said he was not anxious, but was feeling apprehensive about going home this weekend --- because he has to start dialysis at Sunnybrook on Friday next week, very early in the morning at 7 AM. He drew a lot of hair on his head to see what he would look like if he had hair! She laughed out loud, and it was fun.

Next he drew his socks and shoes. Shoes first, then blue socks. Before this he drew the things around him in red. He drew the blood pressure cuff on the left side, the cup holders on the armrest, the TV speaker on the armrest by me. Then he drew the dialysis machine. He couldn't see it very well, and didn't want to use the mirror to see it. So he drew what he could. Then he looked up and I realized he was drawing the machine across the way to get his machine drawing accurate. He drew a circle on the screen representing the filter monitor. Then the cable coming from the blood pressure cuff to the machine. He colored in the BP cuff for fun, and

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completed the machine to the floor. At the end he didn't know what to do, and I noticed he was a bit agitated and tired because of the infection and worry about going home.

I asked him if he wanted to write anything on the map? He started to write no pain, itchy, rash, culture taken, checked by Dr., all in a list beside the dialysis machine and this time he didn't draw anything personal, but he said he would like to thank the staff because they are really great. I suggested that because it was late in his treatment, and that he had already spent a long time doing the body mapping, that he think about drawing the staff in the third and final body map. He liked the suggestion and agreed.

Yana, BM1

March 9, 2012

9:40-10:10am

Began feeling uncertain about what to create on her map. I asked her if she was experiencing any sensation of pain, in her arms, legs, and so forth. She responded, “Yes” and said “today my legs hurt; no other day.” She thought about it for a bit and then drew where she was feeling pain on her right leg—but she drew it on the left side on the body map. She seemed to think that was the right side, so, it’s okay. She used dark green marker to label the area of pain. It is an outlined area, versus shaded in. she didn’t want to use red because it looks like blood, like she’s bleeding, which would be scary for

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someone on dialysis. The dark green areas were the ones with the most pain, similarly to how pt 6 indicated her pain. I would have to ask her in the interview why she chose not to use red. She said it felt like a cramp, so maybe dark green represents aching, deep, sick pain, as she said it was?

After this, she drew pain on her shoulder area and down her arm. She drew water lines over her stomach because she is getting fluid drained today at Sunnybrook hospital from her abdominal area. Then, she drew some indication of pain on her foot—she said that it is at the top of her foot. After this, she drew her tulips in her room that she received from her friend. They were orange and bright green. She drew the vase too. It was drawn in blue, because there is water in the vase. However, the water lines that she drew resemble that of a sad, frowning face, which is interesting.

The tulips face upwards and one faces away from her, maybe to indicate some variety in the arrangement, but it might also be a subconscious drawing indicating that the tulips, though they are beautiful now, they will eventually pass? Her friend brought them for her on International Women's Day (March 8th). She didn't want to draw her portrait, but said that she feels "tired in her head," so I asked her what colour she would use to represent this feeling? She was unsure at first, but agreed that grey or blue would work. She chose grey. She started to draw the top of her head with lines, jagged

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lines, and so forth. Then, she drew her eyebrows and eyes. I said, “oh, you’re drawing your portrait!” She smiled, and said, “oh yes.”

She finished, drawing her nose, and mouth, smiling. After this, she didn’t know what else to draw. I suggested to try drawing the dialysis machine, but she was too tired, and said it was “very complicated”. I asked about her choice of green for pain, why she chose that versus red? She said it’s a good idea to use red. So, she might not have been focusing at the very outset, and chose any colour. She drew red around the green line on her food and around the water on her abdomen. She left the leg/hip and shoulder.

The doctor came by to check on her and by then she was almost done. She drew a red line below her chin on her chest, across to her shoulder and back to her head and said that this is where she feels very warm. She might have meant the other side, where the central line is located, but I’m not sure; I think this is case of body side disorientation. The doctor was curious to know what the patient was doing? I asked the patient, out of confidentiality, if she wanted to share her map with the doctor? She said yes. She said, “I draw this because it hurts here and her, down here (her shoulder). The doctor asked about the different colours. I said green is an intense pain, red is painful, but not as intense as the green, and blue represents the water that she is having removed today at Sunnybrook. The doctor examined the

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map inquisitively to understand her pain. It was great. I left and they continued to talk.

APPENDIX E: BODY MAPPING WITH TOUCH SCREEN TECHNOLOGY

On June 25, 2011, I designed a prototype body mapping application in an interactive animation program, “Adobe Flash CS4” using Actionscripting 2.0, which is a coding language that enables a participant to interact with the animation using a computer mouse, or, in the case of a touch screen computer, with their finger (Figure 19). The design was adapted from a drawing application tutorial online by Luka Maras (<http://flashexplained.com/actionsript/making-an-interactive-drawing-sketchpad>, 2008).

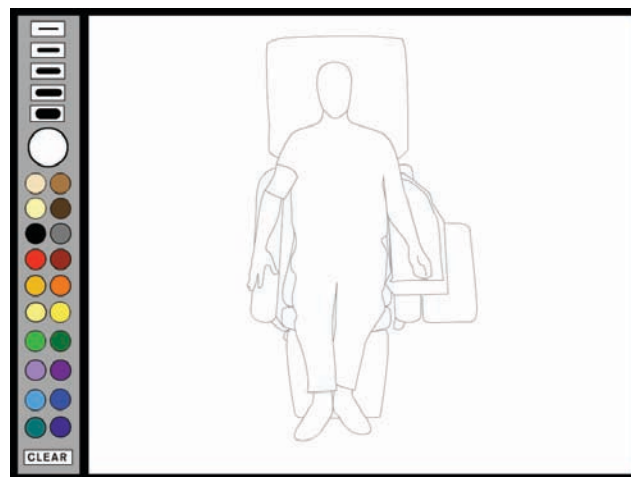


Figure 19: Body mapping touch screen application prototype

The intent of designing this application was to try body mapping before collecting data, as I was unsure of how well body mapping would work with the participants, and how I should approach facilitation. Solomon recommends that the facilitator have their body outline traced and to try mapping on their own before facilitating the actual session with participants in her facilitator's guide (2007). Therefore, I tried body mapping with this prototype, and realized that some of the prompts that Solomon suggests to use in the body mapping sessions did not need to be asked at all during the body mapping sessions (2007).

After mapping, I thought that the prompts by Solomon were too narrow for my study, and decided to approach the sessions more openly to find out what results would come out of the sessions naturally. I felt it was better to allow the participants to explore body mapping on their own so that they could learn about their body experiences independently. At the same time, doing body mapping before facilitating the study gave me the insight to be aware of their process and know when to ask questions about participants' drawing and writing, as Solomon advises (2007).

Tablet computers, such as the iPad will dramatically transform how body mapping can be used in future studies, perhaps in a fifth technological approach. The small-scale size of tablet computers supports the needs of participants in body mapping with the psychosocial approach, who benefit

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from a contained process. It will be especially beneficial for people with Post-Traumatic Stress Disorder (PTSD) (Crawford, 2010), or with other mental health conditions that impact on body awareness and perception such as anorexia nervosa (McPhee, 2000). In other cases, body maps can easily be shared between patients and health care providers with tablet computers, in the same room, down the hall, across the country, or in different areas of the world.

APPENDIX F: MY RESPONSE TO THE BODY MAPS



Yana



Carmine



Rosa



Cooper

**No response created for Jean's work.*

APPENDIX G: BODY MAPPING GIVES PARTICIPANTS AN INDEPENDENT VOICE TO EXPRESS THEIR ILLNESS ADJUSTMENT AND EXPERIENCES.

In analysis of the body maps, I found that participants drew their bodies in exposed, or covered ways, using indications of clothing, or not as a way to cover their bodies on the maps. They also drew their body forms and structures deep and superficially. From the body maps, interview data, and literature on illness adjustment styles (Radley & Green, 1987), I found patterns that support the analysis of identifying participants' levels of connection and disconnection in the dialysis unit (Figure 20). Thus, it might be possible to locate participants' illness adjustment styles, and levels of connection/ or disconnection using the method of body mapping.

Considering the four factors of the drawing styles: exposed/covered, and deep/superficial, I found four combined scenarios that are explained from the diagram in Figure 20, and in Table 6. When a participant drew their body forms and structures, they were *exposing* them. Cooper's drawing shows the forms and structures on the surface (superficial) of his body. For example, when he drew "cold" on his collarbone (Figure 13), he expressed an illness adjustment pattern of Active-Denial, which involves "trying to conceal illness from others" (Radley & Green, 1987, p. 189-190).

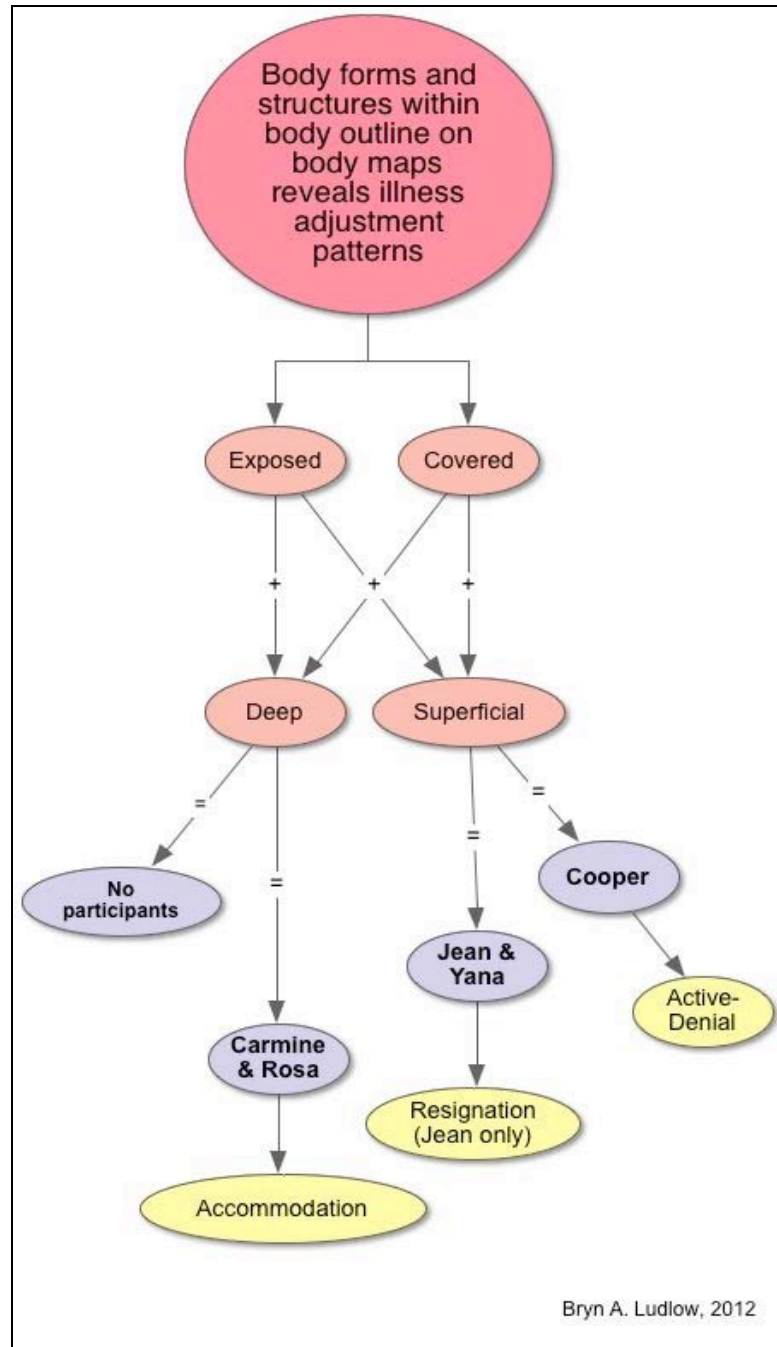


Figure 20: Body mapping reveals illness adjustment patterns

Table 6: Clothing and body forms and structures within body outline on body maps reveals illness adjustment patterns					
I	Exposed	+	Superficial	Cooper	Active Denial
II	Exposed	+	Deep	Carmine & Rosa	Accommodation
III	Covered	+	Superficial	Jean & Yana	Resignation

Aside from his indication of a cold sensation on his body, Cooper conceals his body sensations, and so his body maps reveal his illness adjustment pattern of active denial.

Rosa’s body maps, when analyzed with this diagram (Figure 20) and table (Table 6), do not match her illness adjustment pattern of secondary gain. Rosa’s body maps give voice to how she truly feels, versus in her interview, where she comments on her symptoms of pain and problems, experiences of hæmodialysis therapy, and interactions with her doctor and other care providers. Her body maps *expose deep* body forms and structures, including her heart, gout in her right hand, sore knees, and pain in her intervertebral discs of her sacral (lower) spine (Figure 7). Though her second map has more elements outside of her body, she still exposes deep forms and structures in her body outline. In her third map, she used a bold red line to draw similar forms and structures drawn in her first map.

Rosa's body map reveals an illness adjustment pattern of accommodation, as she is "self-monitoring her rate of recovery" by drawing her problems (Radley & Green, 1987, p. 189). Despite this, her interview exemplifies patterns of secondary gain and resignation. Her body map reveals her illness adjustment pattern of accommodation, independent from her illness adjustment patterns of secondary gain and resignation in response to interactions with her health care team.

Carmin's body mapping exposes deep forms and structures, which match with an illness adjustment pattern of accommodation, as she also, "self-monitored her rate of recovery," naming and labelling her pain and sensations, as well as the severity (Radley & Green, 1987, p. 189). She also expressed other elements of the accommodation illness adjustment pattern in her interview.

Jean's body maps do not explore his sensations experienced in his body while on dialysis. He *covers* his body with clothing, which might indicate that he feels cold, but he did not say, or write this on the map. His portrait drawing shows a sad expression looking away from me, and down to the floor (Figure 15; appendix C).

Yana's body map (Figure 10) shows covering and superficial mapping, which indicates a resignation illness adjustment pattern. Because she only completed one body map, she might have deeper explorations in the

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second and third maps, as Carmine did, which were not discovered because of her withdrawal from the study. This pattern is inferred by her portrait drawing, which faces the viewer and tilts slightly toward me on her right side, which suggests she is engaged in the process (Appendix C).

Her style of mapping is unique, as she outlines her pain in green, and dots lines around areas of pain and cramping in red and blue (Figure 10). But these regions of pain and cramping are superficial; they not say much about her perceived, or known source of her pain and cramping, when compared to Rosa and Carmine's mapping.

The covering, and superficial sharing in Jean's body maps reveals an illness adjustment pattern of resignation. The maps show "feelings of passivity, helplessness or hopelessness" (Radley & Green, 1987, p. 190). Yana's map has covered and superficial areas of pain and cramping, but her portrait is hopeful and inquisitive (Table 6). Without more maps, and an interview, I cannot make a case for any specific illness adjustment pattern expressed in her body map, as it is not clear with the information she has shared.

In this analysis, the varying consistencies between the maps and interview data are interesting. Carmine and Cooper's body maps expressed the same illness adjustment pattern as their interviews. Rosa transitioned from accommodation, to secondary gain, to resignation pattern expressions

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in this one study. In her case, body mapping, compared to interviewing reveals a different patient perspective and voice. Yana's direction in a second and third map might, or might not have gone in a different direction than her first map, and so it is possible that illness adjustment patterns shift over each body mapping session, day by day. This analysis reveals that body mapping gives participants an independent voice to express their illness adjustment and experiences.

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