

**MOTHERS WITH ARTHRITIS:
EXPERIENCES IN THE STORIES OF MOTHERING**

by

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Bachelor of Science (Occupational Therapy)

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

The Faculty of Graduate Studies

(Rehabilitation Sciences)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

April 2008

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ABSTRACT

Motherhood has been described as an identity, a role, and a way of participating in life (Arendell, 2000; Farber, 2004). Motherhood has also been described as 'work', the care taking, nurturing and teaching of children (Francis-Connolly, 2000). Mothers with arthritis have reported difficulty in the tasks of parenting and household work (Allaire et al., 1991; Backman, Kennedy, Chalmers & Singer, 2004; Barlow, Cullen, Foster, Harrison & Wade, 1999; Grant, Cullen & Barlow, 2000; Reisine, Grady, Goodenow & Fifield, 1998), however, we know little about how a mother experiences these challenges. While the subjective experience of being a mother and having a disability is intrinsically linked to participation, health and social interaction (Farber, 2004), research has not been conducted on how mothers with arthritis experience mothering in the presence of arthritis, and how this experience affects their participation, identity and social interaction. This narrative research study asks "How is being a mother and doing motherhood activities affected by your arthritis?" Study objectives include:

- 1) Describe mothers' experiences of nurturing, teaching and caring for their children.
- 2) Describe how mothers understand and explain the effect of arthritis on their role of mother.
- 3) Describe whether or not this understanding changes how mothers participate and interact in their community.

Narrative inquiry was used to explore the experiences of eight married mothers with inflammatory arthritis who have at least one child (aged 0-18) living at home. Purposive sampling allowed representation of families from different communities, with children of different ages. Data collection included two in-depth interviews, participant observation, document review, and fine art painting. Data was coded and analyzed using narrative inquiry techniques (Coffey & Atkinson, 1996; Riessman, 1993; Sandelowski, 1991). Overarching storylines are presented as narratives that describe the mother's experiences of identifying with the role of mother, participation, fatigue and the social context in which mothering occurs.

This study contributes to the sparse body of literature on the impact of arthritis on participation in maternal practices and social interaction, informing health professionals about the experience of mothering with arthritis.

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ACKNOWLEDGEMENTS

I wish to thank Dr. Catherine Backman, Dr. Melinda Suto and Dr. Andrew Chalmers for their tremendous support in my roles of student, research assistant, wife and mother over the last 3 years. I owe particular thanks to Dr. Backman, whose encouragement many years ago facilitated early clinical research and ignited a desire to learn more and encourage other clinicians, who, like me, wonder if they have it within themselves to embark in graduate studies.

The Canadian Arthritis Network awarded me with a Graduate Training Award, which allowed me the gift of studying without financial pressure and supported networking with other students and arthritis professionals.

The School of Rehabilitation Sciences supported my applications with generous financial support in grants and scholarships.

I thank Otto Kamensek for his interest as a consumer and fellow artisan, the Arthritis Research Centre of Canada for their support, and Allen Lehman for his assistance in finding participants and honest feedback. I owe heartfelt thanks to Sharon Smith, my peer reviewer, who assisted me personally and scholastically.

I also thank Lisa Singh who assisted with transcription.

Without the support and encouragement of my family, particularly my husband Cory, and the patience and love of my children, I would not have succeeded.

DEDICATION

**To my daughter, Siobhan,
and my son, Donovan,
who were both born during my studies;
my eldest son, Hayden, my husband, Cory;
and my father,
who valiantly wrestles arthritis every day**

CO-AUTHORSHIP STATEMENT

Linda Del Fabro, under the supervision of Catherine Backman, designed the research program and performed the research, collecting all data with advice from Melinda Suto and Andrew Chalmers. Catherine Backman and Melinda Suto directed and assisted Linda Del Fabro in data analysis. Linda Del Fabro, Catherine Backman, Melinda Suto and Andrew Chalmers were all involved in the interpretation of results and preparation of a manuscript based on Chapter 2 of this thesis.

CHAPTER 1

Introduction

This study focuses on the occupation of motherhood in the presence of inflammatory arthritis. Inflammatory arthritis is a chronic disease which may affect how a mother balances the things she does on a daily basis and how she perceives herself participating in her family and community. This chapter describes motherhood, occupation, participation and inflammatory arthritis and follows with a literature review encompassing the above topics as well as paid and unpaid work, women's health and disability, mothering with arthritis, and ends with a review of qualitative research including reflexivity. Finally, the research question, objectives and relevance to occupational therapy practice are presented. Clarification of the terms motherhood, occupation, participation and identity will be helpful to assist understanding of how a chronic disease like inflammatory arthritis affects being a mother and doing motherhood activities.

Motherhood and Occupation

Motherhood can be described as a work role, involving caring and nurturing; an identity, a responsibility and a relationship. Occupation is a synthesis of doing, being and becoming (Wilcock, 1998). From an occupational therapy/occupational science perspective, Wilcock defines occupation as simply: "...all that people need, want or have to do" (p. 8), for social, physical, mental and spiritual reasons, for survival, for health or meeting obligations, for choice or habit and/or for finding meaning and purpose (Wilcock, 2005). From an occupational perspective, therefore, the occupations of mothering can be viewed as what a mother does (doing), how a mother sees herself (being), and how the experiences of motherhood affect future participation in a motherhood role (becoming). The occupations of motherhood are complex, and may, for example, include assisting children in becoming independent in dressing themselves or in

guiding them through problem solving after an argument with a friend. Teaching and caring are examples of occupations. Some examples of motherhood activities might be washing a soccer uniform, giving choice about what snacks to bring, driving to soccer practice and watching the practice on the sidelines. These activities are undertaken within the occupation of ensuring healthy participation in and learning about team sports. Activities and tasks comprise occupations; occupations together comprise daily life roles.

Doing and being are in constant interaction, and this is essential to health and well being (Wilcock, 1998). The dynamic nature of what we do (our occupations) and who we are (who we understand ourselves to be, our nature, essence and our individual capacities within our occupations) (Wilcock, 1998), is related to occupational identity. Occupational identity is a mosaic of one's occupations over time and encompasses both an understanding of who one is and who one wishes to become (Unruh, 2004) as an occupational person. Hammel (2004) believes that doing, being, belonging and becoming are the backbone of experiencing meaning in one's life, however, being able to 'do' in the areas of self-care, work and leisure are not necessarily the only way of seeking and experiencing purpose and quality of life. Belonging points to the importance of relationships, connectedness, community, reciprocity, and contributing to others. Belonging can support both "...the ability to do and contribute to the pleasure and meaningfulness of doing" (Hammel, 2004, p. 302). This wider understanding of meaning envelops mothering occupations, being a mother, belonging to a community, and caring for and nurturing children into adults. How a mother experiences meaning from and in her day affects her self-perception of who she truly is, or identity. Self-perception, in turn, influences her daily occupations.

Participation and Inflammatory Arthritis

The World Health Organization (2001) defines “participation” as the involvement in a life situation, and “activity” as the execution of a task or action by an individual. Motherhood is a life role. When a mother balances her occupations along with a chronic illness, often the meaning and participation in motherhood is unseen. Exploring both participation in motherhood tasks and identity of mothers with arthritis allows this meaning to be revealed. This study explores the lives of women with inflammatory arthritis, including mothers with rheumatoid arthritis (RA) and mixed connective tissue disease (MCTD). Both RA and MCTD are diagnosed in adults. Pain, stiffness, fatigue, and physical limitations are common symptoms in RA that can lead to changes in psychological well being and social participation across the lifespan (Backman, 2006; Filocamo et al., 2007). Both are chronic diseases which affect the individuals’ physical, emotional, and spiritual health. In much of the literature, however, the focus has been on physical disability, physical dysfunction and the assumed loss of health and quality of life. Recent and later literature on mothering with arthritis will be reviewed to gain an understanding of the complexities of how inflammatory arthritis affects participation and identity in the role of mother.

Literature Review

A literature review of motherhood reveals that research of mothers with disabilities is in the “pre-concept” (Morse, Mitchham, Hupcey, & Tason, 1996) stage of knowledge development. Pre-concept refers to an incomplete articulation of ideas that may lead to a firmer model or theory in the future. In this case, there is a lack of knowledge generated by current research regarding mothers who have disabilities. While “motherhood” as concept may be well-established, recognized and valued to some degree in North America, when it

comes to motherhood with chronic illness, its “characteristics are not fully articulated” (Morse, Mitchham, Hupcey & Tason, 1996, p. 388) in health professional literature. Research exists that describes the experience of mothers with a disability, however, a firm concept including models and sound theory has not yet emerged. Most of this research has used qualitative methodologies and has examined the current meaning of maternal work through participant observation, interview, and learning from the historical perspective of the inequities faced by mothers (Esdaile, Farrell & Olson, 2004; Larson, 2000a; Prilleltensky, 2003; Reid, Angus, McKeever, & Miller, 2003; Wollett & Marshall, 2001).

Motherhood and Mothering Occupations

Motherhood has been described as an identity, a role, and a way of participating in life (Arendell, 2000; Farber, 2004). Motherhood has also been described as ‘work’, the care taking, nurturing and teaching of children (Francis-Connolly, 2000). Childcare includes engagement (physical care and play), accessibility (availability to the child while engaged in another task) and responsibility (accountability for the health, welfare and safety of the child) (Lamb, 1987). “Mothering is an intense, complex and profound human experience” (Farber, 2004, p. 210); it is a “...central component of many women’s adult identity” (Wollett & Marshall, 2001 p.194) and is a source of self-worth. Mothering is undertaken by mothers, fathers and grandparents; it often occurs in the context of unpaid work in families (Primeau, 2000). Culture influences “...what it means to be a mother, what behaviors and attitudes are appropriate for mothers, and how motherhood should shape relationships and self-identity” (Johnson & Swanson, 2003, p.21). As factors influencing women’s decisions about when to have children include individual, familial and societal (Benzies et al., 2006), motherhood itself continues to be influenced by the same factors.

The 'perfect' mother achieves a balance between mothering and non-mothering roles, balancing and juggling occupational goals, family life, and sense of responsibility (Del Fabro Smith, 2005). An assumption that women naturally have an innate sense of skills that emerge as they become mothers, along with the lack of cultural support for maternal work, have left a wide gap in understanding the nature and sophistication of maternal work (Larson, 2000).

Understanding the tasks and activities of mothering particularly how a mother "juggles" the needs of her family simultaneously, has been of interest to some researchers. Ruddick (1995) found that mothers care for their children and engage in household work at the same time, and that the two activities often conflict. However, Bateson (1996) found that as mothering work requires attention to multiple tasks simultaneously, mothers often 'enfold' play within household work. A common phrase for this is 'multi-tasking'. Strategies to enfold both child caring and household work have been described by Primeau (1998). This study aimed to "explore the nature of parents' play with their preschool-aged children and how it was orchestrated within their daily occupations" (p. 188). Ten families were observed for 8.5 to 16.5 hours per family. After the initial observations, each parent was separately interviewed. Primeau found that parents use two strategies to orchestrate work and play within families: strategies of segregation (parent-child play interspersed with household work) and strategies of inclusion (parent-child play embedded in household work). Within household work, children who have "...the access and freedom to participate in scaffolded play" (p. 193) may assist with tossing a salad, setting the table or helping to pull out weeds in the garden. Primeau (1998) determined scaffolded play has two benefits: it expanded parents' ability to interact, spend time, and play with their children, and children were able to do and learn about occupation by engaging in an activity with their parents. The latter, described as occupational scaffolding, is the "...process through which parents foster their children's competence as adults" (p. 193). Larson (2000) uses the term 'orchestration' to describe processes of planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting, and meaning making.

Parents in this study, who had children with disabilities, utilized all eight processes of orchestration “within a single occupation and throughout a day’s round of occupations” (p. 278). Processes were child sensitive, maternally driven, sensitive to the needs of other family members, and considered competing demands. Using these processes, Larson found “mothers make sense of their past, design their present, and plan for their future within their daily occupational rounds for themselves and family members” (p. 278). Larson called for future research using musical metaphors, such as orchestration, that expand on how “persons select coordinated sequences of occupations and shifts in occupation to create daily routines that include rest and inactivity” (p. 279). Similarly, in nursing literature, Wuest (2000) described “re-patterning care”, a process wherein women “re-organize caring activities to reduce or overcome the negative effects of caring demands” (p. 393) within the current sociopolitical climate of health and social reform in Canada. Using grounded theory methodology, Wuest purposely focused on listening to a participant’s positive proactive language versus reactive to describe processes of re-organizing caring activities. “Adjustment” versus “compromise” was given as an example of positive language. Re-patterning care includes anticipating, setting ground rules, juggling time, and relinquishing and replenishing. She stresses the processes are intuitively and consciously acquired, subject to recursive ordering, and revised in response to changing and new demands, including intervening environmental conditions. The processes are also “...concomitant with growth in perspectives, skills and opportunities” (p.397). Wuest’s participants included 21 women caring for themselves and other family members, as well as 43 previously collected interviews with women who had children with health care issues, elders with Alzheimer’s disease, or women who had left abusive relationships.

Both Larson and Wuest’s respective studies are similar in that they provide examples of looking past the question of ‘what is difficult’ to ‘what do you do, and how does it create opportunity’. Much of the literature is focused on the former, to the extent that opportunities to learn are focused on barriers to achieving life goals, versus strengths and strategies of mothers in everyday life

situations. This especially applies to studies on women with disabilities. Defining barriers and deficits is a common thread in past and present studies (see Heidrich, 1996; Noesk & Hughes, 2003). Unquestionably, this research is valuable and offers suggestions for macro and micro changes in health and wellness related services, political change, and socioeconomic policy. However, an understanding of how mothers experience their occupational roles has not been a focus, which may provide information above and beyond how they structure their day to day occupations in the presence of arthritis.

Being a Mother

How mothers achieve “doing” motherhood things, is closely tied to what being a mother means. There is intrinsic value in being a mother, identifying oneself as a mother, and striving to be a ‘good mother’. I propose searching for a “different picture”, one which strives to understand the actual practices and perceptions of mothers and promotes their own ‘adjustments’ to other mothers who do and do not happen to have a disability. Listening and learning from mothers themselves helps us learn how they ‘do’ and ‘be’ mothers (Del Fabro Smith, 2005).

Barker Dunbar and Roberts (2006) recently published a study exploring mothers’ perceptions related to the occupational experiences of mothering. This phenomenological study used focus group methodology to explore the seven mothers’ perceptions of daily family tasks and activities. Four major themes emerged. The first, “socio-cultural impact”, describes the mothers’ reflections of family experiences from their own childhoods, including child rearing practices that actively influence how they mothered in their own families. The second, “activities and occupations of mothering”, describes the “...particular routine in which they engaged, the co-occupations in which they participate with their child, and/or the specific activities they did for their child (ren)” (p. 61). The authors describe a pattern of activity (e.g., making breakfast) that contributes to an occupation (e.g., preparing healthy meals, ensuring healthy eating habits). The

authors note that the way a mother prepares a meal will relay the meaningfulness of that activity to her and her children, and will influence how she does that activity. Building self-esteem, teaching values and life skills, and engaging in self-care activities with children are also examples of areas where mothers may engage in “occupational decision-making” (Barker Dunbar & Roberts p. 63). Occupational decision making, including what is appropriate, healthy and ‘right’, is a part of a mother’s routine with her children. The third theme, “range of feelings”, describes concern, worry, guilt as well as enjoyment, on a “...continuum from negative to positive expressions related to mothering experiences” (p 63). Interestingly, younger mothers were more apt to feel guilt regarding the care of their younger children (leaving them in daycare, spending time with them) than older mothers. The fourth theme, “role management”, describes how the role of mother is supported or unsupported in different contexts. Positive and negative factors exist in social environments and through individuals that help or hinder a mother’s ability to manage her role and feel adequate as a mother. ‘Mothering role support’, previously described by Llewellyn and McConnell (2004), includes helpful individuals and social environments that provide “learning and advice sharing opportunities” (p. 65). Barker Dunbar and Roberts (2006) found that mothers “...identified support and a sense of organization as key factors in their mothering roles” (p. 67), and the needs of a mother as well as the strengths of each parent were considered to support the needs of the children. Spouses, extended family, neighbors, and family members able to ‘be there when you need them’ were seen as supportive. Negative influences included feelings of inadequacy in the mothering role, unhelpful spouses, or conflicts with other roles. The authors note that mothers are “concerned with their children’s successful participation and interaction with other children” (Barker Dunbar & Roberts, 2006, p. 66). One participant found that a neighborhood family’s involvement soon after their move was ‘like a hug’, and helped her feel that her family was accepted in their new neighborhood. This study builds on the understanding, or lack of understanding towards mothering occupations.

The study of occupation and motherhood is a relatively new area of scholarly activity. Esdaile and Olson (2004) edited a textbook examining the occupations of motherhood which aims to increase the understanding of mothering occupations. Motherhood from a wide range of perspectives is examined, and includes mothering occupations undertaken across the life course from a qualitative research and clinical perspective. Everyday challenges, and mothering in the context of special challenges (such as mothering children with disabilities, and mothers who themselves have disabilities) brings to light mothering with different physical and mental health abilities and external influences. Occupational science, feminism, and phenomenology strongly influence this text; in as much as it can, this volume focuses equally on the strengths and difficulties faced by all mothers.

Paid and Unpaid Work

In the last fifteen years, there has been increasing interest in the 'work' of mothers. The occupation of mothering and related tasks have been influenced by a past preoccupation with the value of the 'stay at home mom', purported to be the ideal in the 1950's (Larson, 2000a). Additionally, all families are not reflected through the heterosexual norm of one woman/one man parents. While more than half of mothers work outside of the home in Canada, (Statistics Canada, 1995), some studies have reported that this ideal is still influencing suggestions that part time work outside of the home or mothering full time at home is best (Johnston & Swanson, 2003; Vincent, Ball & Pietikikainen, 2004). Although raising children includes productive and socially valuable labor (Craig, 2006), mothers are not given economic consideration because their work is considered 'nonwork'; useful and necessary, but not always respected (Grace, 1998). Household work, or unpaid work, has been historically undervalued and less evaluated than paid work; however, it is extremely important to our society as it is the primary source of nurturing and services related to activities of daily living for the family (Allaire, 1991; Larson, 2000a). Unpaid work can include domestic work, child care, other

care, household maintenance and even volunteer work (Beaujot & Lui, 2005), an example of which may be coaching a child's soccer team or involvement in parent participation committees. Depending on whether the family adopts traditional (mother at home full time, father working) or other division of labor practices (dual income, single parent-earner, etc.) the occupation of household work is balanced among family members in certain ways. The distribution of unpaid work, however, tends to fall to women, who are still carrying out the greater proportion of unpaid work in the home even if they take part in paid work (Primeau, 2000; Craig, 2006; Vincent, Ball & Pietikainen, 2004). In terms of housework, women still maintain the largest share of core housework (meal preparation, clean up, indoor cleaning and laundry) according to Statistics Canada (2005). Women's daily participation rate for core housework is 85%, or an average of 4.4 hours per day; primary childcare and shopping for goods and services adds another two hours. At the same time, women's paid work outside of the home continues to increase. Their participation rate in paid labor is 81%, about 5.4 hours per workday (Statistics Canada, 2005). Working mothers are faced with a 'double burden' and "...the change in women's labor force participation has not been accompanied by an equal change in the division of unpaid work" (Beaujot & Liu, 2005, p. 925), especially with children 5 to 18 years of age (Beaujot & Liu, 2005). Work-family conflict, a relatively new area of study, examines the culturally influenced phenomenon of particular stresses on the dual income working family (Marks, Husten, Johnson & MacDermis, 2001; Maume, 2005; Sidebotham, 2001). Mothers as 'earners and carers' are particularly susceptible to role overload (Cunningham-Burley, Backett-Milburn & Kemmer, 2006). Balancing paid and unpaid 'mother work' is demanding, time consuming and requires a balance of roles and expectations within the paradigm of motherhood: a social construction, defined within social, economic and historic contexts (Arendell, 2000) but unique to each individual.

Women's Health and Disability

Women's health issues have not been fully addressed in empirical studies (Angus, 1994; Kreigher & Taylor-Brown, 2001; Odette et al., 2003) or holistically in the clinical community (Opachich & Savage, 2004). This includes both the responsibilities of motherhood and adaptation to a disability or chronic illness. In the case of mothering with a disability, identifying key characteristics and attributes requiring attention is problematic due to the lack of understanding of mothering characteristics in general.

New mothers may expect to be guided by those with expert knowledge, until they develop an expertise of their own. To do so requires disengagement from the 'experts' and a reliance on supports within their home and community (Miller, 2003). When a mother is also balancing the effects of a disability, this support becomes crucial to her ability to engage in mothering activities. In the presence of a chronic illness or disability, women face challenges in both the "doing" of mothering occupations and "being" a mother. That is, there is the potential for both task-related and role-related problems. Challenges include physical limitations, inadequate social support, societal attitudes and lack of resources, psychosocial factors, and presumed deficiency in parental role functioning (Kelley & Sikka, 1997; Nosek & Hughes, 2003; Odette et al., 2003). Disabled women with children may have their motherhood challenged by lack of inclusion into natural maternal communities such as young mother's support groups (Farber, 2004). Women may feel guilty about the impact that chronic pain has on their families, may not balance care of self with care of family members (Smith, 2003) and may have more difficulties in completing day to day parenting tasks when compared to women without chronic pain (Evans, Shipton & Keenan, 2005). A presumption of disability that extends into mothering occupations is a barrier because mothers may not be seen as practical problem solvers (like most non-disabled mothers), but as mothers with limitations arising from their disability (Alexander, Hwang & Sipski, 2002; Grue & Tafjord Laerum, 2002). This makes "doing" motherhood in an ordinary way within mainstream motherhood challenging (Grue & Tafjord Laerum, 2002). The presumption of disability is

evident from the researcher's perspective as well, especially in literature prior to the year 2000. Family functioning is affected by culture, personal and financial resources, available coping mechanisms and past history (Hough, Lewis & Woods, 1991). It would seem mothers with impairment are not treated with the same presumption of ability as mothers without, even when areas of their lives reside outside of the impairment itself. If for example, a mother's ability to walk is impaired by a physical disease, this may not impede her ability in the activities of cuddling and reading her child stories; the occupation of settling a child into bed for the night. This is an area of research that needs to be explored. Present research does not address how women meet the needs of their families, juggle 'outside the home' work and motherhood if they are also balancing their lives with a disability caused by an impairment or societal presumptions.

One model put forward in the last few years accounts for the intersection of phenomenology, participation, social interaction and health experienced by mothers with disabilities (Farber, 2004). In this model, phenomenology is the subjective experience of being a mother and having a disability. Participation is individually valued, culturally common maternal practices. Social interaction is the mother's sense of community, experience of help, and the normalizing or marginalizing she experiences. Health is the perception of health, and the severity and frequency of illness symptoms. These four constructs intersect and are subject to changes over time. Farber (2004) notes that there are many other influences (not yet fully defined) that affect her model of mothers with disabilities: the external physical environment, access to technical assistance or new adaptive parenting equipment, and external and interpersonal environmental supports. Notwithstanding, Farber's model begins to discern how mothers with disabilities perceive themselves, engage in social interaction, participate in the role of mother, and manage their illness. More critical appraisal, data collection and dialogue need to occur in order to advance her model, or otherwise develop a relevant, culturally sensitive and meaningful theory, as there is not enough literature or empirical support at this time. Defining the concept of mothering with

a disability has not precluded early research initiatives, but one could argue that definition may assist in informing and focusing future research.

Mothering with Arthritis

Women with chronic illnesses are faced with tremendous challenges and choices in attending to their own health needs while preserving the integrity of their families (Opacich & Savage, 2004). Mothers with arthritis have reported difficulty in the tasks of parenting and household work (Allaire, Meenan & Anderson, 1991; Backman, Kennedy, Chalmers & Singer, 2004; Backman, Del Fabro Smith, Smith, Montie & Suto, 2007; Barlow, Cullen, Foster, Harrison & Wade, 1999; Grant, Cullen & Barlow, 2000; Reisine et al., 1989) however, we know little about how a mother experiences these challenges. Employment and household work disability has been reviewed within the arthritis population in a small number of studies. Most literature agrees that household work is negatively impacted by the presence of arthritis (Allaire, 1991; Allaire et al., 1991; Backman et al., 2004; 2007; Berson Rosenthal, 1996; Giorgino et al., 1994; Reisine & Fifield, 1998); however, the impact of arthritis in the context of parenting is not well understood (Barlow et al., 1999; Grant, 2001; Katz, Pasch & Wong, 2003). In an earlier study of mothers with RA, mothers had concerns about the inability to perform activities for and with their children (Allaire, 1988). However, in the majority of the literature, past and present, the perspectives of others including physicians, family members and therapists have outweighed the concerns of the mothers themselves (Barlow et al., 1999; Grant, 2001; Katz et al, 2003; Reisine & Fifield, 1998).

Research is largely focused on problems or challenges encountered by mothers. Studies of mothers with arthritis have identified feelings of inadequacy, guilt, anxiety, lack of confidence, a growing sense of frustration, psychological distress, and anger about fulfilling their mothering roles (Allaire et al., 1991; Barlow et al., 1999; Grant, 2001; Katz et al., 2003; Kelly & Sikka, 1997; Reisine & Fifeild, 1998). There is minimal literature on motherhood and arthritis focusing on the presence of positive feelings, such as hope, self-assuredness, positive

thinking, or positive adaptation. Thorne's 1990 qualitative study with sixteen mothers who had chronic illness (some with arthritis) found "...many of the mothers believed that chronic illness afforded some advantages" to their children, including a heightened capacity for compassion (p. 215). Backman, Del Fabro Smith, Smith, Montie & Suto (2007) found participants attributed arthritis as "...beneficial in raising responsible and sensitive children" (p. 385). Generally, however, arthritis parenting literature, especially prior to the 1980's, is not replete with similar examples. In one essay titled, "Social Implications of Rheumatoid Arthritis in Young Mothers", Chamberlain (1979) states, "All toddlers need adventure, experience with sand, water, and external environment. But the mother can't take her children to the park—if she can even get there; they may fall into the pond" (p. 71). While this is humorous and perhaps somewhat true, depending on the situation, the 'problem' appears to reside with the mother. It is clear that research needs to examine all parts of a mother's experience, positive and detrimental, personal and environmental.

In recent studies, some progress has been made in the area of what is meaningful and important to people with arthritis, however, there is little focus on motherhood, parenthood, or participation. Dubouloz, Laporte, Hall, Ashe & Smith (2004) published a qualitative study examining personal beliefs, values, feelings and knowledge (meaning perspectives) in the arthritis population. This study identified the meaning perspectives of people with RA and found they inform the changes people make in their daily activities: what is important intrinsically determines what choices are made in every day pursuits. A second qualitative study described what is important when living as a woman with RA from a clinical rehabilitation perspective (McPherson, Brander, Taylor & McNaughton, 2001). This study of ten women utilized grounded theory analysis to uncover five themes that explicate the process: personal/intrinsic factors, external/extrinsic factors, future issues, perceptions of normality and taking charge. The model developed features a central theme of 'taking charge' with the other themes encircling it. The authors note the paucity of locating positive issues in the lives of people with arthritis in current research. The weaknesses of this study include

lack of triangulation with regard to data collection and minimal quotes representing the participants' voices, but it does aim to present positive and negative substantive themes.

From the review of literature summarized above, areas of concern for women with RA on a daily basis have been overlooked. As well, how a mother identifies herself, by what she does and who she is, is not adequately described. If occupational identity is not only associated with work, but also with unseen and seen roles, responsibilities, and meaning, understanding mothering with arthritis remains an area of unanswered questions.

One study that partially addresses these questions describes themes of seeking help, searching for meaning, and uncertainty about day to day symptoms affecting roles, dependency on others and altered relationships outside of the family (Brown & Williams, 1995). The extent and nature of problems with parenting are described in another study, a survey of parents and grandparents (n=448) with ankylosing spondylitis (AS) and RA, but mothers are not specifically singled out (Grant, Foster, Wright, Barlow & Cullen, 2004). The study indicated that 75% of the population studied was female. Direct quotes illustrate the lack of help and support available to participants with RA, and some adaptive strategies to cope with childcare challenges are featured. This is a good start in identifying the specific experiences mothers face in their occupations.

Backman and colleagues (2007) published a qualitative study of twelve mothers with inflammatory arthritis that reflects concerns as well as seen strengths from the mother's perspective. Using grounded theory, this study describes the limitations in household work and parenting tasks resulting from chronic rheumatic conditions. Mothers described the difficulty of physical work, creative ways to manage, level and type of support they needed, the impact of fatigue, positive and negative influences their participation had on their family, and patterns of relinquishing and adaptation in mothering occupations. Mothers in this study reported positive feelings as well, for example, a sense of pride in seeing their independent children (Backman et al., 2007). The resultant dynamic model shows the interaction between participation in mothering tasks (shown on

a continuum, with one end “sometimes I can” and the other “sometimes I can’t”) with the impact on the family (beneficial/problematic), balancing energy and fatigue (manageable/disabling), and kinds and level of support (effective/ineffective). This explanatory framework is a beginning for further study in mothering in the presence of a chronic illness as it portrays the interaction between the level of a mother’s participation with other factors previously reported.

Fatigue is a factor associated with parenting difficulties in some studies (Barlow et al, 1999; Grant, 2001; Katz et al., 2003). While a measure exists to determine self reported fatigue in persons with arthritis (Belza, 1995), the related research is based on older adults, who have different social roles and daily routines. The level and impact of fatigue on the roles of mothers has only recently been explored (Backman et al., 2007) and fatigue may be experienced differently by women with arthritis than by healthy women. In a phenomenological study of 25 women with and 25 women without fibromyalgia (FM), Sodberg, Lundman and Norberg (2002) found that women with FM saw their ‘body as a burden’ (jaded and losing energy), ‘an absence presence’ (uncontrollable feeling; one of constant sleepiness), ‘an interfering obstacle’ (pain giving fatigue and fatigue giving pain, a lack of strength directs relationships and daily activities), and ‘hope for the end or relief of pain’. Women without FM saw tiredness as a natural occurrence needing recovery time and rest. Backman and colleagues’ (2007) study of 12 women with arthritis found that fatigue was described as overwhelming: one participant described wanting to hide in clothes racks when shopping to rest. The balance of energy and fatigue was ever present, and deeply affected the level of participation in mothering activities (Backman et al., 2007) and in many aspects of their lives.

Examining the relationships between physical disabilities and other experiences of social support, sense of self, role strain and parenting is a new area of study. Fyrand, Moum, Finset & Glennas (2002), in their study of 264 past hospital patients, describe the impact of physical disability and disease duration on the amount of social support and daily emotional support received by women

with RA as an inverse relationship. Reisine and Fifield (1998) found that depression is associated with the loss of valued activities, not just functional decline; however, it is unknown how women experience their mothering role when valued activities are changed, lost, or substituted. Physical disability, as it relates to participation in motherhood roles and tasks, is not well understood. Some studies have reported that physical impairments often present in inflammatory arthritis (IA) make it more difficult to cope with the demands of children, especially preschoolers, who require assistance with feeding, bathing and dressing (Barlow et al., 1999; Ostensen & Rugelsjoen, 1992). A quantitative measure has been created specifically to measure the relationship between disability and parenting activity (Katz et al., 2003); however, longitudinal results have not yet been reported. As motherhood activities hold intrinsic and extrinsic value, the impact of disease related factors on the ability to participate exists in all occupations of mothering (Backman et al., 2007; Katz et al., 2003).

Qualitative research

Not only is it important to discover how arthritis affects mothers' experiences of carrying out mothering activities (participation), but observing actions in the context within which mothering with arthritis occurs helps to make implicit meanings visible. Qualitative research allows exploration of experiences using specific methodology, resulting in deeper understanding of a phenomenon (Reissman, 1993). The goal of analysis in this study is to gain insight and accurately represent the way mothers understand and enact their lives through one or more story, told in the context of mothering with arthritis, and then describe the storylines accurately as narratives, looking for similarities and differences across participants.

Some clarification of terms may assist in understanding the analytic process. The terms 'narrative' 'story', 'account', 'life story' and 'life history' are often used interchangeably. For the purposes of this study, narrative inquiry or narrativity (Frank, 2004) is the research tradition that guides data collection,

analysis and representation; narrative analysis encompasses the systematic analysis (Reissman, 1993) of each of the story lines of participants within their larger life story as mothers. A narrative is the researcher's rendering (Porrier & Ayes, 2007) based on the complete analysis of the participant's story.

'Doing' narrative research

Within narrativity, there are many perspectives regarding how to actually 'do' narrative analysis. Narrative analyses are distinguished from other forms of qualitative analysis by their emphasis "...on how an experience is told, not the informational content per se" (Sandelowski, 1999, p.82). As such, "...ways in which narratives are constructed, configured and contextualized... become key defining features of narrative inquiry" (Miller, 2003 p. 19). I asked, "Why was the story told that way?" (Reissman, 1993, p.10). These features that become subject to analysis include linguistic choices (striking vocabulary, key words, key metaphors), what the story revealed about the story teller's circumstance, character portrayal, omissions, long pauses, verb tense, incoherent or chaotic dimensions, contradictions, and key tensions within and between stories (Coffey & Atkinson, 1996; Gee, 1991; Labov, 1972,1982; Labov & Waletzky, 1972; Power, 2004; Reissman, 1993; Sandelowski, 1991). In other forms of qualitative analysis, many of these features are omitted; the text is fragmented into "thematic categories for coding purposes" (Evardsson, Holritz Rasmussen & Riessman, 2003, p. 379). In narrative analysis, structural qualities are sought out and lay form for the subsequent production of narratives.

One well-known criticism of qualitative research as a whole is the absence of a detailed analysis plan presented (Higgenbottom, 2004). With this in mind, my primary work as a new researcher was to determine how to thoughtfully create a data analysis plan, supported by published scholarly research. My goal was to clearly answer the question, 'How did you get there?' and leave a clear path with supporting evidence so that processes could be scrutinized, replicated, and therefore demonstrate methodological rigor. While there is no 'recipe', an understanding of narrative analysis from different perspectives, including Gee

(1991); Reissman (1993); Sandelowski (1991); Coffey & Atkinson (1996); and Labov (1972,1982) enabled me to utilize the genre that allowed me to gain the deepest insight from my participants.

Gee (1991), whose interest lies in the theory of units of speech, allows linguistic choice, changes in pitch and intonation, discourse markers to locate narrative forms and functions. For example, one participant in this study stated,

"I can't participate in all of the activities they want me to do, like tobogganing—/ that's mostly because of **the** hips, I've had **them** replaced---/ **so** it really does limit—**ah**---/ and fatigue wise, I get **sooo** tired. (P1)

In this part of the told story, the word "the" is striking. The participant utilizes 'the,' 'it' and 'them' to describe her hips in the context of participation, which, compared to the other coherent stories within the larger told story, mirrors many examples of how she sets aside her arthritis and filters the content of her participation experiences in the way she teaches her children. Also interesting is her use of 'so' and 'ah', paralinguistic devices that, when isolated, determine when she is moving on to the next 'stanza', or idea. The emphasis she places on the word "so" is also repeated within the transcript. Applying Labov's structural analysis, (1972, 1982), which includes segmenting each story into five parts (abstract, orientation, complication, evaluation, resolution and coda), "I can't participate in all of the activities they want me to do, like tobogganing—" is the orientation, "...that's mostly because of the hips, I've had them replaced—" is the complication (what occurred), and "...so it really so it really does limit—" is the evaluation, significance or meaning of the action.

Following analysis of each of the stories as told, the next phase of narrative analysis allowed the research question to be asked of each story. The observation notes, reflexive notes, field notes, art, and art narratives were reviewed to support or refute these true stories. During analysis, it is the researcher's work to apply understandings of other research findings, theories, and understanding of similar or contrasting situations during the critical assessment and interpretation of the participants' stories (Pyett, 2003). Other

valued data, including the art stories, document review and observation notes/diagrams were also analyzed and added to the narratives to achieve a “full bodied” result (Sandelowski, 2002). Additionally, at this stage the researcher will use continuous reflexivity and ask the question, “Is my interpretation true to the data?” and “How might my knowledge, position, and experience be shaping my analysis?” (Pyett, 2003, p. 1171). Each participant’s stories are treated separately, until the last phase, when narratives and major storylines are constructed from the researcher’s interpretation of the stories as told by the participants (Frank, 2000), as the “...story refers to the tale as a whole, and narrative as the created structure of a story” (Poirier & Ayres, 2007, p. 552). Narratives were compared across participants, and similar narratives are grouped, forming main story lines across participants, analogous to themes. Rigor during data analysis included a detailed audit trail, confirming results with participants, peer debriefing, and ensuring referential material adequacy (Lincoln & Guba 1995).

Qualitative research is well-suited to this line of inquiry as it provided a framework or understanding the intricacies inherent in the experience of mothering with arthritis. Qualitative research encourages the researcher to develop an intimate understanding of participants (Charmaz, 2004) and allows participants the freedom to fully describe their experiences from their own unique and distinct standpoint (Frank, 2000). Moreover, qualitative research seeks to answer questions that stress how social experience is created and given meaning (Denzin & Lincoln, 2000). Apart from the work of motherhood, such as childcare and household work/management, it was important to capture motherhood as both a social role and ‘way of being’ as affected by chronic illness. Far from being formed in a vacuum, motherhood experiences can provide evidence of societal influence, parenting culture, and current mothering discourse which in turn ultimately shape and determine what and how experiences are self-portrayed. As such, particular attention needs to be paid to select research methodologies that are sensitive to the nature and needs of women (Guerrero, 1999).

The aim of qualitative research is to provide a coherent, illuminating description and perspective on a phenomena; qualitative research does not seek to measure but to understand, represent and explain something (Pyett, 2003; Ward-Schofield, 1993). Because the goal of the present study was to learn from the experiences of mothering in storied form, narrative inquiry provided the opportunity to explore each mother's accounts without fragmenting them into smaller comparable parts with the aim to develop a theory, such as in grounded theory methodology. Phenomenology, the research tradition which aims to discover the lived experience of participants, is another different yet suitable choice of qualitative methodology compatible with the study goal. However, narrativity was chosen because of its focus on intra-participant depth within accounts together with story preservation. As grounded theory and phenomenology have different intentions and underpinnings, it is important to be consistent and thoughtful to the aims of a study when considering which research approach to take (Holloway & Les Todres, 2003).

Reflexivity

Researchers engage in a collaborative process with their participants; each brings their own experiences, interests and reasons for engaging in research (Hammersley & Atkinson, 1995; Warr, 2004). Reflexivity is the process of reflecting on the products of this participation (Banister, 1999; Hammersley & Atkinson, 1995). Sword (1999) suggests that by constantly engaging in the research reflexively, "...a personal awareness of how research is shaped by one's own biography" (p. 270) can be created.

As a student researcher, mother and an occupational therapist, many of my experiences in these roles affected how I gained access and trust, asked questions, observed, and analyzed data. As a mother, I 'live' the physical and emotional needs of small children. As an 'insider' to mothering issues, I was privy to deep sharing that may have been more limited otherwise. If "...story tellers tell stories to remind those who share their form of life what it is they share..." (Frank, 2000, p. 361) then perhaps a 'mother-researcher', if declaring my

motherhood, may have reminded mothers to story one experience and not another. The goal was to allow the interview to unfold as a collaborative process, one aided by shared "...gender, class, cultural congruity..." as described by Riessman (1987, p. 190). Motherhood was an unspoken yet understood backdrop.

As an occupational therapist, I have training and interest in participation in daily activities in the presence of disability. Ely et al. (1991) state the need to "unlearn and relearn what we believe to know about how to conduct and interview" (p. 58). Participants, as well, are well-trained in the medical or clinical interview. Having had experience conducting the structured clinical interview in practice, I had to re-learn and accept long silences, pauses and false starts or asides as valuable to understanding the full story. I utilized self-cuing to sharpen my listening to hear areas I knew rested somewhat outside of my academic interest and training, such as the influence of chronic illness on the social fabric of families. The awareness and declaration of my position 1) allowed a fuller understanding of the participant's stories as told; 2) minimized the distortion of the findings by my practical interests and own experiences; and 3) clarified what and how my views and ideas affected the research process. Power differences, gender differences, generational, educational, class, and 'race' differences between myself and the participants cannot be eliminated, even with shared experience. The short time spent with the participants is asymmetric by nature and may lead to "the potential for relationships to end abruptly and for participants to feel that they have been misunderstood..." (Kirsch, 2005, p.2164). Recognizing and reflecting upon the dynamic research process, positive and negative, will allow reflexivity to become a circular pattern of thought and action, a 'good habit', and illuminate all processes, assisting with realistic expectations with regard to the interactions with participants (Kirsch, 2005) and analytic activities. Lastly, there is a scholarly consideration: declaring my values, beliefs and background offers a context within which audiences can more fully understand my interpretation of the research findings (Sword, 1999), to what

extent my perspective has influenced the text (Seale, 1999), and make clear my ontology.

Research Purpose and Objectives

This qualitative research study attempts to understand how being a mother and doing motherhood activities is affected by a diagnosis of inflammatory arthritis.

The objectives of this study are to:

- 1) Describe mothers' experiences of nurturing, teaching and caring for their children.
- 2) Describe how mothers understand and explain the effect of arthritis on their role of mother.
- 3) Describe whether or not this understanding changes how they participate and interact in their community.

Relevance

Mothers with arthritis need to be heard, acknowledged and valued. Mothers may feel less isolated knowing they share similar experiences. The main value of this study will be to document mothers' voices and add consumer perspective. As there is currently little information available to mothers with arthritis on how to manage their mothering roles, the study will offer practical suggestions from mothers who have "been there", leading to greater advocacy and ability to seek appropriate services.

Research findings will be of direct use to health care professionals. Therapists look to professional literature and evaluate their knowledge against it. This enables them to develop services that will better address the challenges their clients face; in this case, the challenge of parenting for mothers with arthritis. Arthritis management is often a partnership among health care professionals, consumers and their families. It is anticipated that an in-depth study of mothers with arthritis will yield not only descriptions of challenges, but also identify how the experience of having arthritis as a mother helps or hinders women in coping with the effect of chronic illness while fulfilling the role of

mother. This knowledge could enhance self-management programs and educational materials for use in both urban and rural communities or innovative internet-based support groups for others with arthritis. Research that acknowledges the mothers' "voice" will enhance this partnership. Through sharing detailed descriptions of tasks, roles, meanings and strategies, the participants can inform professional practice and add to the knowledge of health professionals. Findings will help occupational therapists and other health professionals to advise clients with arthritis on approaches to full participation in the role of parent. Additionally, by exploring the experiences of mothers with arthritis, the knowledge gained may guide further study on related issues, such as the impact of arthritis on the role of fathers and the effect on children growing up with a parent who has a chronic illness.

The subjective experience of being a mother and having a disability is intrinsically linked to participation, health and social interaction (Farber, 2004). Research has not been conducted on how mothers with arthritis experience mothering in the presence of arthritis, and therefore, how this experience affects participation, social interaction and health. Mature concepts can be linked together to form the building blocks of theory; theory informs research and practice (Morse et al., 1996). The concept "mothering with a disability," has not reached full maturity; adding to the professional literature regarding mothering with arthritis may draw us closer to developing a mature theory, and thus, inform professional practice.

Specific mothering occupations that have meaning and value to women need to be understood. How mothers perceive mothering occupations influence how mothers participate in their every day activities (Barker Dunbar & Roberts, 2006). The proposed research will focus on the mothers' perspectives, their narratives, their values and their perceptions of how disability may change their participation in the roles and activities of motherhood. The illness experience is as unique as each individual; as is motherhood. Thus, it is only with an understanding of the personal challenges that the strengths and needs of each mother can be adequately addressed.

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CHAPTER 2

Belief in Doing and Knowledge in Being Mothers with Arthritis¹

Motherhood has been described as an identity, a role, and a way of participating in life (Arendell, 2000; Farber, 2004) and as 'work'; the care taking, nurturing and teaching of children in the context of unpaid work in families (Francis-Connolly, 2000; Primeau, 1998). Childcare includes engagement (physical care and play), accessibility (availability to the child while engaged in another task) and responsibility (accountability for the health, welfare and safety of the child) (Lamb, 1987). From an occupational perspective, the occupations of mothering include what a mother does (doing), how a mother sees herself (being) and how the experiences of motherhood affect future participation in a motherhood role (becoming). Doing, being and becoming contribute to a sense of occupational identity, described as the mosaic of one's occupations over time which encompasses both an understanding of who one is and wishes to become (Unruh, 2004). Research has not adequately explored how women with inflammatory arthritis (IA) experience their occupational identity as mothers. Women with arthritis report physical impairment, fatigue and lack of support in their roles, which contribute to difficulty balancing daily motherhood tasks and activities (Backman, Del Fabro Smith, Smith, Montie & Suto, 2007; Brown & Williams, 1995; Grant, Foster, Wright, Barlow & Cullen, 2004). Physical limitations make it difficult to cope with tasks such as feeding, bathing and dressing young children (Barlow, Cullen, Foster, Harrison & Wade, 1999; Grant, Cullen, & Barlow, 2000) and in the related activities of household work (Allaire, 1991; Allaire, Meenan & Anderson, 1991; Backman, Kennedy, Chalmers & Singer, 2004; Backman et. al., 2007; Berson Rosenthal, 1996; Giorgino et al., 1994; Reisine & Fifield, 1998). Most literature agrees that the impact of arthritis in the context of parenting is not well understood (Barlow et al., 1999; Grant, 2001; Grant, Cullen & Barlow, 2000; Katz, Pasch, & Wong, 2003).

¹ A version of this chapter will be submitted for publication. Del Fabro Smith, L., Suto, M.J., Chalmers, A. & Backman, C.L. Belief in doing and knowledge in being mothers with arthritis.

Fatigue, described as "overwhelming" and "all-encompassing" is a factor associated with difficulty parenting with arthritis (Grant, 2001; Grant et al., 2000; Katz et al., 2003; Backman et al., 2007). While self-reported fatigue in persons with arthritis has been documented (Belza, 1995), the level and impact of fatigue on the role of mothers has only recently been explored (Backman et al., 2007; Katz et al., 2003).

The level of participation and support in motherhood activities in the community affects perception; mothers with disabilities may face barriers to inclusion in motherhood communities (Farber, 2004). However, positive interpersonal connections and high role quality can mediate arthritis related disability in women with RA by increasing psychological well-being (Plach, Heidrech & Waite, 2003). When effective, support from family, friends and health professionals enables them to participate in mothering tasks (Backman et al., 2007). However, the relationship between support and inclusion within their community and the maintenance of occupational identity is unclear.

Mothers "orchestrate" their occupations (Larson, 2000) to plan what and how they will care for their children. This involves balancing, anticipating and planning family needs and desires that should be accomplished on a given day. While mothers with arthritis describe patterns of relinquishing and adaptation in mothering occupations that affect their everyday participation (Backman et al., 2007), we do not know how being a mother with arthritis influences creativity and resourcefulness in the orchestration of motherhood occupations, and in turn, how this affects everyday participation and identity.

Finally, past literature has documented difficulties, challenges, hardships, and differing coping styles used by women with IA (Allaire et al., 1991; Barlow et al., 1999; Grant, 2001; Katz et al, 2003; Kelley & Sikka, 1997; Reisine & Fifield, 1998). Little is known of the presence of positive feelings or positive adaptation. One ambition of this study is to identify and represent a balanced view of participant's lives through motherhood stories and experiences.

This narrative study is concerned with how mothers with arthritis experience participation, social interaction and identity within parenting roles.

While the subjective experience of being a mother and having a disability is intrinsically linked to participation, health and social interaction (Farber, 2004), research has not been conducted on how women with arthritis experience mothering in the presence of arthritis, and therefore, how this experience affects participation, social interaction and self-perception. The objectives of this study are to:

- 1) Describe mothers' experiences of nurturing, teaching and caring for their children.
- 2) Describe how mothers understand and explain the effect of arthritis on their role as mother.
- 3) Describe whether or not this understanding changes how they participate and interact in the community.

Method

Study Design

Story telling is viewed as an important way that individuals reflect on and make sense of past experiences. Women, in particular, use story to construct and play out their roles as mothers (Tardy, 2000). As such, narrative inquiry, a specific form of qualitative research inquiry based on the propensity of humans to narrate or "story" their experiences in their daily lives (Mischler, 1996; Ricoeur, 1981; Sandelowski, 1991) guided the study design. The focus was on collecting stories about motherhood from women who are mothers with arthritis.

Participant Eligibility and Recruitment

Women were eligible if they: 1) had a diagnosis of inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis, juvenile idiopathic arthritis, ankylosing spondylitis or mixed connective tissue disease), 2) were over the age of 19 years, 3) had at least one child living at home (aged 0-19), and 4) were able to converse easily in English.

Purposive sampling ensured participants represented different family sizes and geographical locations. Women were invited to participate by three methods: letter from their rheumatologist, word of mouth notification, or letter of invitation to women who had participated in research in the past and had indicated interest in participating in future research. Ethical approval (Appendix A) was provided by the Behavioral Research Ethics Board of the University of British Columbia, Vancouver, BC. Participants signed a consent form before the first interview and were provided with a copy (Appendix B).

Data Gathering

Extended time with mothers through multiple observations, intensive interviewing, document review and use of innovative data collection (participants produced and narrated a small painting) in their home and communities by the primary author allowed exploration of the patterns of participation in motherhood activities. Detailed data collection and management methods can be seen in Appendix C.

I (the primary author) approached research as an interactive and collaborative endeavor (Warr, 2004) assuming that people tell stories to someone and for someone (Frank, 2000). As an occupational therapist and mother, I reflected on how my ideas, theoretical interpretations and views affected the research process and product (Banister, 1999; Hammersley & Atkinson, 1995; Sword, 1999). The process of reflexivity was aided by keeping a detailed journal, consulting with co-authors and a peer reviewer during data gathering and analysis.

Two interviews were conducted with each participant, before and after the participant observation period, consistent with guiding principles regarding interviewing women (Guerrero, 1999; Riessman, 1987) and active listening (Poland & Pederson, 1998). The purpose of the interviews was to understand the meaning given to mothering and perceptions of how women participate in mothering with arthritis present. The questions asked during the first (45-90 minutes) and second (20-30 minutes) interviews followed from an overarching

lead question each time: “Can you tell me what it is like to be a mother living with arthritis?” and “You have had some time to consider being a mother living with arthritis. Is there anything else you would like to tell me about?” Main questions and prompts are included in the interview guide (Appendix D). Both interviews and field notes were audio recorded and transcribed directly after interviews. Recordings were listened to and simultaneously compared to transcribed manuscripts at least twice for accuracy.

Between interviews participant observation activities were scheduled, including ‘everyday’ activities such as meal times, children’s sporting events, playtime, walks and driving to and from school. The aim of participant observation was to explore different aspects of each mother’s life including planning and engaging in mothering tasks. Detailed field notes were taken during the visit and then organized into a chart format which included the type of observation, the duration in each activity and researcher reflections. Document review included looking at photo albums, family pictures, and children’s school documents such as art projects. The aim of document review was to encourage another way to understand and explain the effect of arthritis on mothering.

During the last visit, mothers were given all materials necessary and all the time they wished to paint a simple picture in response to the question, “What are the most important things about being a mother?” While this data collection method has been used to understand chronic illness (Guillemin, 2004), in this case it served as a method of self-expression, bringing closure to the research process. The stories about the paintings and paintings themselves (Appendix E) were summative, drawing upon what is important and valued instead of what is difficult and challenging. Further analyses of these data are not possible here due to space limitations, however, observations during this data gathering method is in Appendix F.

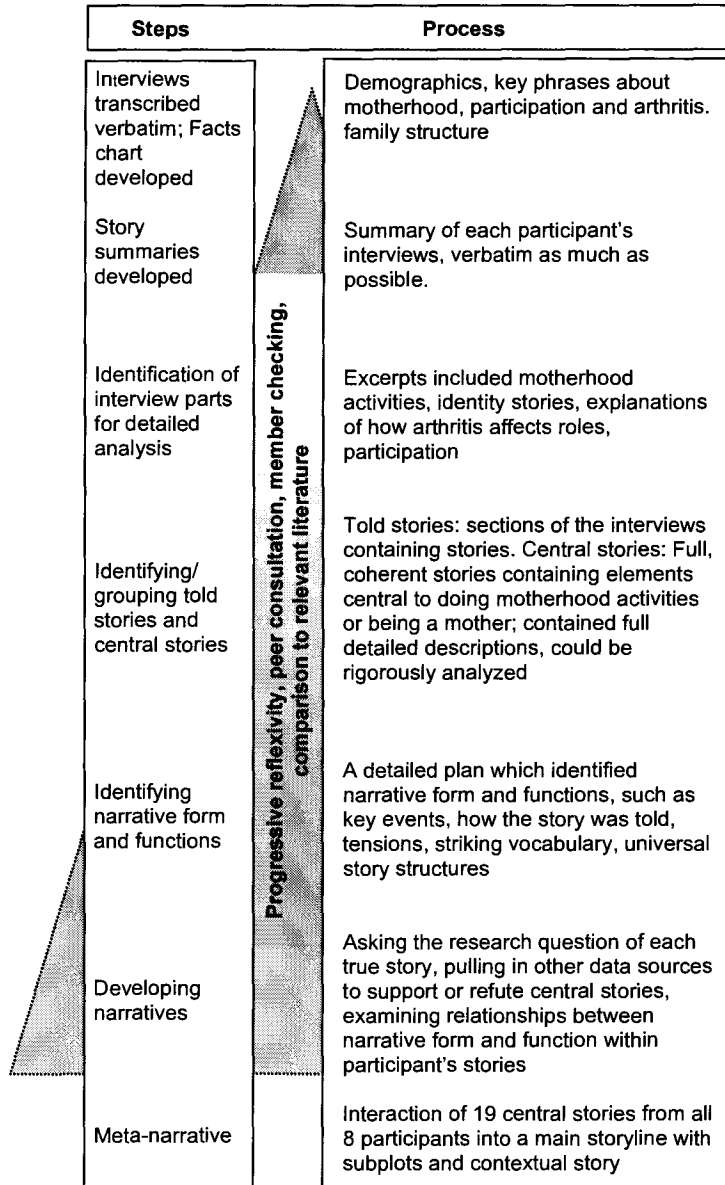
Data Analysis

Principally, the work of Reissman (1990, 1993), Gee (1991), Labov (1972, 1982), Labov and Waletzky (1972) and Coffey and Atkinson (1996), were drawn upon to formulate a data analysis plan (Figure 2.1). The detailed data analysis plan (Appendix G) included four separate processes:

- 1) preparatory analysis: producing a summary for each participant, developing a facts chart;
- 2) locating an edited version for narrative analysis: organizing the data, locating the 'told' stories;
- 3) intra-participant analysis: locating the 'central' stories: the central true stories for each participant, asking the research question of each of these stories, deep analysis including identifying common structures/structural properties, and finding narrative forms and functions, producing the researcher narratives; and
- 4) cross-participant analysis: comparing narratives across participants to find main storylines, or narratives analogous to themes.

Each participant's stories were treated separately until the last phase, the construction of individual narratives (central story summaries) (Appendix H). This analysis process was aided by a flow chart for each participant (Appendix I). The individual narratives, or central story summaries, were compared and grouped to create the meta-narrative; the main storyline and subplots, representing the researchers' interpretation of the stories as told by the participants (Frank, 2000). Narratives were compared across participants, and similar narratives were grouped, forming main story lines across participants, analogous to themes. Rigor was enhanced by detailed and thorough documentation, confirming results with participants, and peer debriefing with co-authors and a peer independent from this research team (Lincoln, 1995), creating a traceable audit trail. Making the research process visible and allowing systematic scrutiny assisted to validate the research process (Bailey, 1996), ensuring trustworthiness.

Figure 2.1. Data analysis plan



Results

Participants. Table 2.1 outlines characteristics of the eight participants, all of whom were married. Seven had RA and one had mixed connective tissue disease (MCTD). All were under the care of a rheumatologist. Based on observation of the neighborhood of residence, and participant statements about financial difficulties or lack thereof, the sample included women from lower, middle and upper middle class socioeconomic households.

Table 2.1. Participant Characteristics

Pseudonym	Age	Age, in yrs, and sex of children	Geography ^a	Work status/profession
Carly	42	2 (F) 4 (M) 5 (M)	Urban	Home F/T/ Classroom assistant
Barb	45	10 (F) 13 (M)	Urban	Home FT/ Teacher
Uta	27	3 (M)	Rural	Home FT/ Disability aide, group home
Sara	40	7 (F) 9 (M)	Urban	Teacher P/T
Kim	35	10 (F) 8 mos (F)	Urban	Maternity leave/Nurse
Taralyn	38	12 (F) 4 (F)	Rural	Home F/T/ travel agent
Hannah	40	14 (F)	Urban	Work P/T/ banking
Alex	30	10 (M) 6 (M)	Rural	Work P/T/ retail

^a Classification of home town according to Statistics Canada (2002).

Findings are presented in the form of a meta-narrative, the integration of 19 central stories through the analysis process. The meta-narrative is comprised of a main storyline, titled “Just Because I Can’t Do Doesn’t Mean I’m Not a Mom” and reflects the overall findings about doing and being a mother in the presence of arthritis. This meta-story, or main story line is presented first, followed by its two sub-plots, participation and fatigue. The last section, a smaller contextual

story referring to the social contest described by participants, represents the backdrop or frame. The narrative analysis resulted in two to three central stories for each participant, represented in Table 2.2. Appendix F includes the central story summaries, or narratives, for each participant.

Table 2.2 Central stories and synopsis for each participant

Central stories	Synopsis
1) Falling down, I can't get up 2) The learning game: "I think just like plain old motherhood, it's a learning game as you go along"	1) A 'tragic' story, referring to apprehension of falling in public and being unable to get up, and being at "the mercy of others" to help 2) This phrase was used to label various examples of how Carly adapted to her physical limitations, but also described the process of parenting with arthritis as similar to other mothers
1) Cooking: The same for everyone but slightly more overwhelming for me 2) "Not everyone has to be the soccer star family"	1) Refers to planning, shopping and making meals for Barb's family and for larger family gatherings 2) A sense of relief and certainty regarding her family's agreed upon involvement in soccer
1) "It's so different for me" 2) Sleep, energy and learning: "We'll lie down together"	1) Following 'cavalier' stories of how Uta has to approach everyday parenting activities, she describes herself as "different" because she needs to do things in other ways as compared to others without limitations 2) An energy conservation story, resting with her son
1) It hasn't gotten in the way 2) I always wanted to be a mom	1) ...of doing activities with her family, things Sara really wants to do 2) A story of conceptualizing being a mother before she had children
1) "We've done a lot—a lot to adapt to make it better. So that's good" 2) "I'm not always able to do the things but I make up for it."	1) This success story includes the mother (Kim), her two daughters, and her husband, all adapting in different ways to facilitate family life 2) "things" include physical activities with her older daughter, caring for her infant daughter, making up is ways she is involved and present when active participation is not possible
1) "I'm part of it, but just not in the same way" 2) "We're just going to have a day" 3) Things that are not as important, I let those things slide, or others kick in	1) Success stories that describe being part of Taralyn's daughters lives through observing and volunteering in ways she is able 2) Describes a day of putting errands and housework aside to play with her 3 year old daughter 3) A story of adjusting expectations and seeing help from others Describes processes of evaluating what she needs to do (childcare, household work), and putting less important things aside or asking for family members for help
1) "Watching her evolve has been amazing" 2) "She talks to us about everything"	1) Describes the process of seeing Hannah's young daughter grow up and mature 2) Describes the openness between herself, her spouse and her daughter in general, but through a particularly difficult situation
1) "I don't want sympathy, just a little understanding and patience." 2) "The hardest part is the emotional part": not playing soccer with my family and worrying about my sons getting arthritis	1) A story of Alex's frustration regarding others expectations for her, particularly in her son's sporting activities and the expectations of involvement as a parent 2) The emotional aspect to dealing with arthritis and parenting is illustrated through two stories of activity and "worry"

Main Storyline: “Just Because I Can’t Do Doesn’t Mean I’m Not A Mom”

This meta-narrative commences with stories grouped and labeled “I always wanted to be a mom”. Carly’s painting, featuring both her own handprints and those of her children’s, captures this centrality of being a mom:

“Well, it’s just the hands of my three kids and myself...we are all connected, all joined...with me the mom being the focal point and the kids are all together. My hand fits on top...as the basis, the grounding, the keeping them together, the anchor...”

Being a mother was described by the participants first and foremost as an identity: being a mother in the presence of arthritis, as opposed to stories of pain, disability and dysfunction. They portrayed themselves as knowledgeable in being mothers, that “I AM a mom”. The strength of this identity seemed to allow mothers to negotiate their lives in the presence of arthritis without losing the ability to see who they were, to themselves and to their children.

The Connection Between Doing Motherhood Things and Being Mothers.

Mothers balancing parenthood and arthritis provided profound examples of the interconnectedness of being and doing; when the ‘doing’ of motherhood activities was challenged, it disrupted ‘being’ mothers. This became most apparent when their roles as mothers included participation in physical activities which demanded energy and agility. Alex, who is not able to play soccer with her two young sons stated, “The hardest part is the emotional part” arising from her physical limitations. She worries about her ability to participate and encourage her sons in activities they enjoy, such as soccer and bike riding. She is also troubled about her children’s ability to understand the disease. Her story was told with a sense of concern about being an “involved” mother. Barb’s story of making dinner for her family and friends also speaks to the interconnectedness between being and doing. Cooking represented being present with her family and extending hospitality to guests, but was also a difficult activity due to related fatigue. She used the word “overwhelmed” in ‘being’ a mother during this

occupation. Thus, the fluidity of being and doing, and how they influence and inform one another, is a dynamic process interrupted by chronic inflammatory arthritis.

Subplot 1: Participation: Engaged in a life role

Many of the stories held a description of how mothers' physical involvement had been limited, but then resolved with a strategy that worked around arthritis symptoms and harmoniously with their aspirations to be involved with and encourage their children: to be engaged as mothers. Concepts within this participation subplot include "being there", belief in doing, planning participation (planning, deciding, anticipating and forecasting) and ways of engaging (active observation, side by side activity, inclusive/structured play, and listening/teaching).

"Being there". Participation was primarily described as 'being there' for their children, encouraging them emotionally, cognitively and physically. The greatest joy was to watch them grow and experience life, and to be a source of consistent encouragement:

"...to be available to them when they need me, to teach them how to be independent, how to manage certain situations by themselves instead of having to come to mommy all the time---nurturing, caring, loving, discipline, limits, all of those kinds of things." (Uta)

Alex's painting, a garden with trees, flowers, a rock wall and a gate, describes her sense of 'being there' for her two sons:

"I was thinking about my garden, and that it is really where I like to be. I like going out into my garden to relax, and I have a hammock that's out there. And the boys—they don't like helping me but they like to ask questions about the flowers and they like to be out there and enjoy the sun. That's kind of one of the things that we do that is special. "

Thus, participants maintain the identity of being a mother by participating in ways that contributed to self-identity as a mother.

Belief in Doing. Women saw their participation with their children on a continuum of not affected to greatly affected by arthritis. Sara said "...arthritis hasn't gotten in the way; I still try and do things". She pushed off discouragement, stayed in the present moment, and viewed her level of participation normal, even "good" through success stories. Other mothers perceived that arthritis profoundly affected their level of participation, but found ways to participate, or 'do' regardless. Mothers relayed a sense of belief in what they could do, despite fatigue, pain, or physical limitations caused by arthritis. A belief in the "I do" is shown through their linguistic choices: We "do it together" [with husbands/partners]. "I do whatever I can". "...we try to do pretty much everything that would make [my daughter's] life fulfilling." "I take the time to do the things that I want to do with my kids". "You just do what you can do [for children] ---get around it". Mothers also described "bonuses" to having arthritis. In explaining her painting, Barb said, "I put a silver lining on the clouds on the arthritis side, because there are positive things, it's not all bad...I'm at home with my kids, and that's a definite plus. And also I am less stressed." Arthritis sometimes necessitated a "slower day", and spending more valued time in activities that allowed kids to learn. Mothers also described children who were empathetic to others with disabilities. Moreover, mothers characterized their children as "helpful": children would help with unloading groceries, making meals or caring for younger siblings. Mothers attributed their children's actions and perceptions as directly related to "having a mom with arthritis".

Planning Participation. Although participating was framed as 'being there', the way participants described planning many activities was complex, taking much into consideration: other people, weighing the possibilities and deciding through planning, deciding, anticipation and forecasting.

Barb related, "It's not like I can say, 'Lets go!', because there are so many things to consider". Mothers considered, and then decided what and how to participate. They asked themselves, 'What am I able to do?' They weighed how meaningful participation in events or activities was for them personally and to their children. Women learned to gauge their ability and interest in participating in many ways; however, arthritis universally brought uncertainty into their daily routine. In the consideration phase, mothers thought of the 1) needs/desires of their children and family, 2) manifestations of energy and fatigue, 3) timing (the day, the number of hours involved, standing, sitting and walking time), 4) relative comfort of the physical setting, 5) how long it will take to 'recover' physically, and 6) whether they will say "I may make it" or "I don't think I can make it because of my arthritis".

The level of thought and consideration preceding participation was striking, especially if it involved others outside the nuclear family. Larson (2000) describes women's processes of planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting and meaning making as an 'orchestration' of occupations. Orchestration was heavily weighted toward planning and balancing for participants in this study. In planning, mothers classified past activities into "try and fail", "try and hurt" or "try and succeed", and then allowed past activities to weigh into future planning/balancing processes:

"...I think it's at a point now where it's very balanced...you either know you can't do it [golfing, hiking], or you think it would just be easier if I didn't push myself to do it [sitting on the floor], or try to do it and then fail [biking]. So I just do other things instead that I know I can do". (Sara)

Once a plan had been made, changing, modifying or eliminating parts of this 'plan' was a step taken before participation. Resting the day before, asking for help from family or arranging drop off of a preschooler or teen to school by someone else were all ways of anticipating and forecasting beforehand.

Ways of engaging. Participation was described as an engagement in a life role; mothers engaged in “being” mothers through actively observing, learning and adapting (“the learning game”) side by side activity, and inclusive/structured play. Many of these activities were interwoven with listening, teaching, and comforting. Being an ‘observing’ mother was a cognitively active role. If physical involvement was not possible, mothers often supported their child’s activities by observing and/or offering assistance through verbal/instructional guidance. The goal of encouraging their children was often enacted through seeing them learn, providing encouragement and deciding how to further encourage or dynamically participate in activities in the future.

“The learning game” was a phrase used to describe and explain the process of learning (for the future) and adapting (in the present) ways in which mothers engaged with their children in certain activities, both in the moment and in the weeks or months to come. For some, biking, hiking, walking, getting down on the floor or bathing/dressing infants was often described as challenging. Amidst real challenges, mothers often portrayed themselves as learners, taking initiative to seek help and solutions to the common caring and nurturing activities of motherhood that worked for themselves and their families. Collectively, women’s stories about learning had a definitive tone: ‘If this happens, this is how I deal with it’. Carly has had arthritis for many years and described this as a normal process:

“...just learning as you would with anything else, just like plain old motherhood, it’s a learning game as you go along. And you just have to learn the things that work for you and be open to trying a whole bunch of different things”.

Mothers taught their children to climb up on their laps, choose their clothes for school, or ask older siblings for help. Uta described creative ways in which she rested while at the same time encouraging her three year old son to learn to “do for himself”:

“Sometimes he’s being stubborn and I ask him, ‘What do you want for breakfast?’, and he’s not wanting to tell me, so I say, ‘OK, you get out what you want (and I’m not getting out of bed until you have it out), and then I’ll come make it for you’ ... he can reach most of the stuff.”

“The learning game” focused on the needs of both child and mother, and meant adopting a more relaxed schedule, planning outings when energy was highest, or adapting the way an activity was undertaken. The latter reflects most mothers’ mindsets and perceptions of their identities as participating mothers: mothers acknowledged they could not always participate, but believed they could still “be part of it” or “make up for it”. Another aspect of “the learning game” included processes of adapting to fluctuations in energy, fatigue and physical manifestations. Many women achieved this through three related conscious and unconscious processes: re-calibrating parenting activities throughout the day, adjusting their expectations and seeing help from others as a choice. Taralyn, who has 12 and 4 year old daughters, says, “...I just have to let some things go... I just can’t do all the things I would normally do. Things that are not as important, I let those things slide, or others kick in”. She evaluates the importance of activities in her mothering role on a daily basis, adjusts her expectations, and then “calls in the cavalry to help out” if need be: a friend, her extended family or her husband. Eliminating, re-scheduling, shortening, or actively observing were ways of she learned to adjust.

Side by side activity and inclusive/structured play. Many mothers also described side by side activities that matched their physical ability and energy levels on a certain day. Uta described seated activities, such as making pies with her three year old son. Barb and her daughter walk short, planned distances together with the family dog. Often, the limitations of arthritis seemed to create the opportunities for caring as more time was spent side by side with their children. Many of the participants’ children automatically occupy close physical space and interact at eye level; their side by side activities encouraged clear communication and shared goals. Children were observed being included in a structured

household task beside their mothers, such as setting the table for dinner. These side by side activities often included a play component and a teaching component.

Subplot 2: Fatigue

Another subplot of the major storyline is described in stories of fatigue in the daily lives of participants. Taralyn describes “going” until she is prompted by a family member to rest:

“... sometimes I do it, but I usually fight it and I just say ‘no, I can get through this, I’ll just keep going’. But then... if it gets really bad, to a point where you say, ‘oh, that’s it, I just can’t do it anymore’... I go take a bath and go lie down and...try to get through it”.

Sara painted a tree with two sides, and stories fatigue this way:

“And so the leaves on the motherhood side are a little brighter and fresher. In the picture it shows the branches being sort of tired and broken, which is what my limbs feel like... The roots are a bit stronger on the motherhood side, the arthritis side I don’t feel as stable”.

Mothers described the lack of energy as the ‘biggest thing’, requiring constant balance with the needs of their children; affecting their ability to organize play, or attend to caring activities:

“The fatigue plays into it a lot, because there are times that I am just too tired to sort of get up and get another drink, or take them to the playground...So it’s probably rough on them that Mommy can’t just take them out all of the time. They are not old enough to completely understand yet.” (Carly)

In contrast, a few mothers described fatigue as something they live with daily, and describe their need for rest as part of their normal routine, similar to what other parents might experience:

“...fatigue is one of the worst parts about it but when you’re a parent you are tired most of the time anyway, right? So sometimes I am just more tired than someone else might be, but you know, you just have to live with that...” (Sara)

Fulfilling what participants wanted to do and needed to do with their children was interrupted by fatigue, and mothers described this impacting their enjoyment and sense of accomplishment in being mothers. Thus, fatigue was a complicating factor, disrupting the cycle of doing and being.

Stories of Social Contexts: “They Just Don’t Get It” and “The Motherhood Club”

The contextual story has two parts, both focusing on how participation in child-related and motherhood activities in their communities was influenced by how others understood their lives as affected by arthritis. Mothers’ occupations take them into certain settings (school, grocery store, church, community centre, work) in their physical, spatial and geographical community. Using a theatre analogy, mothers interact with their immediate family and friends (supporting roles) and teachers, neighbors; church members, co-workers, other mothers, and children’s coaches (the ‘extras’). In the larger community, mothers may also interact with an ‘audience’: other people within the frame engaging in similar occupations at the same time.

“They Just Don’t Get It”. Within a particular setting, mothers perceived other people observing them and expecting certain things of them in their role of mother. During interactions, mothers wondered ‘What do I think of what other people think of me?’ Mothers also asked; ‘Looking at other’s expectations for me specifically, what can I be doing or not be doing, and how does looking ‘normal’ affect what is thought/expected of me?’

In the larger community, stories were told about the 'audience' not understanding their limitations, stories of "they just don't get it", "they don't even think [I may not be able to do it]". "It" meant their ability to maneuver through a store, attend or host neighborhood family barbecues, or volunteer at their children's schools. Uta, who sees herself as 'different' and a crusader, shared a comedic story about shopping with a friend who is visually impaired:

"I'm in my wheelchair with [son] in my lap, and she's bumping into people because she can't see and people just look at you and think you're being rude, and think I'm the one with the problem...and it's just so funny, the stereotypes...it's interesting, going out and people scowl at you. But—I don't know, people need to be more educated..."

Alex, who lives in a small rural community with two young sons, related how the coach of her son's soccer team doesn't understand her limitations because she 'looks normal'. When asked to help, she described her response: "...well, nothing physical, but if you need anything done otherwise, I will do it---I can stand on the sidelines and cheer, I can do stuff, but don't expect me to kick the ball or run after it". Despite this, she was then asked to be assistant coach, a very active position. Her wish was to have people know she is capable, and can do "most stuff" but asks for "...a little patience and understanding" not sympathy, from those asking her to do things she may not be able to do. Other mothers echoed this: they felt that because they looked 'normal', people automatically expected them to engage in activities demanding their time and energy that were unrealistic.

This pattern of misunderstanding was frustrating to most mothers, not because they were unable to do what was asked of them, but because those asking sometimes ignored the ideas mothers put forward about what they were able to assist with. Mothers saw themselves as able and willing participants; when they were included and encouraged to participate in other ways, they often found 'my place' and a sense of accomplishment. Some mothers decided to volunteer in other ways: leading guided reading exercises at their children's

school, leading a Girl Guide group, or driving children to group activities. Thus, a larger societal view of motherhood is also present; often there was an expectation from others based on what a 'normal' mother would do (Larson, 2000) interwoven in the larger story. If a perception was negative, mothers responded on a continuum ranging from "people need to be more educated" to avoidance of the setting: "I don't go, it's not a big deal". Clearly, if mothers are given a chance to enact their ideas of involvement within their children's activities, there are intrinsic and extrinsic benefits to both the organizations and the mothers' sense of worth.

Inclusion Into the 'Motherhood Club'. To be part of a motherhood community, or included in relationships centered on motherhood, was important. Taralyn said:

"...it's almost like you've become part of a special club. A special group...you have so many things to talk about in common with other mothers and it seems like all we do is talk about our kids".

In contrast, Kim felt isolated from her maternal community:

"...I have lots of friends but I don't do a lot with my friends. There's a few friends that understand that I'm tired or...I could make plans, but...I'd change them if I were tired...and some people can think that that's selfish or snobby."

Many women's stories also reflected a pattern of feeling 'guilty' for not reciprocating visits, or feeling awkward having to cancel a planned visit. All mothers learned to focus energy in certain spots, typically devoted time to their children, and "pull out" of other commitments, such as entertaining and socializing. This resulted in fewer invitations, but often, a smaller but more highly valued maternal social network.

Discussion

This meta-narrative is comprised of a main story line, two sub-plots, and the social context in which the participants fulfilled their role as mother. The main story line, “Just Because I Can’t Do, Doesn’t Mean I’m Not a Mom” highlights the inextricable connectedness between doing and being (Wilcock, 1998). Wilcock asserts being and doing are in constant interaction; the dynamic nature of what we do (our occupations) and being (who we understand ourselves to be, or nature, essence and our individual capacities) within our occupations (1998). The research question, “How is being a mother and doing motherhood activities affected by your arthritis?”, assumes that ‘doing’ and ‘being’ cannot be separated into distinct parts of occupational identity. The findings supported this assumption; however, the strength of the connection was not anticipated by the researcher. Participants maintained their identity as mothers through participation (subplot 1) which relayed a belief in involvement in a life role, but not necessarily physical participation. Active observation, side by side activity, inclusive/structured play, learning for the future and adapting in the present (“the learning game”) were examples of how they fulfilled the role of a mother, encouraging their children’s proficiency in all areas of life. Mothers in this study used opportunities of side by side activity with instructional and play components, or inclusive/structured play to encourage their children’s development and to teach them about common household tasks. This is similar to occupational scaffolding, or the “...process through which parents foster their children’s competence as adults” (p. 193). Primeau (1998) determined scaffolded play has two benefits: it expands parents’ ability to interact, spend time, and play with their children, and children are able to and learn about occupation by engaging in an activity with parents.

Anticipating is described as “foreseeing eventualities and taking preventative actions” (Wuest, 2000); and similar to “anticipating” and “forecasting” within orchestration of occupations (Larson, 2000). When role

fulfillment was interrupted by fatigue (subplot 2) within the cycle of doing and being, participants anticipated and rebalanced activities.

Orchestrating occupations was incredibly taxing due to the lengthy consideration processes of how to engage in mothering responsibilities. Added to potential challenges caused by arthritis-related symptoms, planning and engaging in motherhood activities was often far from straight forward. Efforts to understand and acknowledge the orchestration of occupations by clients may improve the applicability of occupational therapy recommendations, and subsequently empower individual clients to maintain or enhance their involvement in valued life roles such as parenting. By focusing simultaneously on different ways of doing mothering tasks and factors that contribute to the sense of being a mother, versus the activity itself, mothers in this study offset many of the negative effects of arthritis, and created opportunities for learning and adapting to the sometimes overwhelming manifestations of arthritis. The occupational performance process model (Fearing, Law, & Clark, 1997) includes the step of identifying strengths and resources for each client. Consistent with this step, health professionals who focus on what the client knows to be true to their occupational identity and what they know how to do, rather than their limitations, may be a critical component to helping them fulfill their roles. Practically, help for mothers in planning of occupations while acknowledging the need of mothers to say 'I can't do that' or 'I may be able to' may assist in shifting the focus on abilities and inherent strengths.

Farber (2004) described mothers with disabilities aligning themselves to a "normal mother" or "not normal, and OK to be different". In contrast, 'normalcy' in this study was described through perceptions of others seeing participants as physically normal, and having unrealistic expectations. Mothers themselves did not necessarily see themselves as being a mother with a disability, preferring to define themselves principally as "being a mom". This study aligned with the findings of Dubouloz, Laporte, Hall, Ashe & Smith (2004). In that study, meaning perspectives (personal beliefs, values, feelings and knowledge about oneself) affected choice in daily activities or occupations with people who experience

inflammatory arthritis. The meaning perspective in the current study can be described as a belief in “I Do” which buoyed participation in mothering activities despite the negative effects of arthritis. Noting how the study participants described meaning perspectives and participation in other ways may help clinicians to see beyond overt activity to the extension of meaning placed outside of ‘doing’.

Fatigue and physical disability led to fluctuating levels of participation, but often not a total elimination of valued activities, expanding on findings in other studies of mothers with inflammatory arthritis and fibromyalgia (Backman et al., 2007; Plach, Stevens & Moss, 2004; Soderberg, Lundman & Norberg, 2002). Mothers in this study described difficulties in everyday activities associated with caring for children, similar to other research reporting on limitations (Barlow et al., 1999; Grant, 2001; Katz et al., 2003; Grant, Cullen & Barlow, 2000; Backman et al., 2007) but also described ways around typical participation by re-patterning activities and adapting (“I’m still part of it, but in a different way”). “Re-patterning care” is a process women use to re-organize caring activities to diminish and prevail over the “negative effects of caring demands” (Wuest, 2000, p. 393), and includes anticipating, setting ground rules, juggling time and relinquishing/replenishing. Mothers in this study adjusted, or “re-patterned” parenting activities in response to the changing manifestations of arthritis versus to overcome the negative effects of caring demands. Mothers were forward thinking, positive and tactical in working around these barriers, and “reconstructed” mothering occupations as found with other mothers with chronic illness (Opacich & Savage, 2004). Similar to re-patterning processes described by Wuest (2000), mothers described these ‘tactics’ and adaptations as consciously acquired during active observation, and naturally acquired over time: “I know there are things that I do differently than I used to do...it becomes so much a part of my life, I don’t see it as different anymore.” As experts in adapting and re-patterning daily occupations, occupational therapists are suited to creating an atmosphere of support and collaboration during this re-patterning process, an opportunity that,

according to the present study's participants, would be welcomed by mothers with arthritis.

Some mothers, such as Carly, found it "tough" to give up the physical activities, especially when there were not resources in place to facilitate specific activities and interests of their children. While consequences of the effects of arthritis physical participation should not be ignored, it may be suggested that placing the focus on losses may impede the ability to see the possibility for re-patterning and orchestration that would still support one's belief that she was being a mother. Building on strengths related to recognizing alternative ways of being a mother, while accommodating fatigue and physical limitations may be incalculably important, as 'being able to 'do' in the areas of self-care, work and leisure is not necessarily the only way of seeking and experiencing purpose and quality of life (Hammel, 2004). Occupational therapy interventions could be revised by listening to stories to more appropriately consider the client's inherent strengths, ensuring adequate observation time within the mother's home environment, and providing as much practical information regarding mothering occupations as possible. As mothers themselves had many ways to re-pattern occupations, developing a way to share these ideas and other information, as well as provide peer support, may also be a worthwhile consideration. A web based 'chat room' for mothers, may be helpful, as van Uden-Kraan et al. (2008) found 37 women with breast cancer, arthritis or fibromyalgia who participated in online support groups reported empowering processes such as exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement .

The strengths of this study include the multiple data collection methods, enhancing the trustworthiness of the findings. The systematic approach to reflexivity on the part of the principal investigator, together with peer checking by the co-authors and a colleague outside of the investigative team, further enhanced the analytical rigor. Participants were mothers of children 8 months to 14 years and lived in both rural and urban geographical areas, and findings may be applicable to other mothers with similar characteristics. Nevertheless, as is

typical of qualitative inquiry, results represent the experiences of these particular mothers and may not be generalizable to others. Limitations of this study include shortened time between meetings with four participants, which may have limited the amount of reflection and disclosure that could occur by the second interview. Because participants were not from a differing cultural or ethnic backgrounds and all were married, this limits applicability to other groups such as single mothers. However, this study does present opportunities to learn about mothers with arthritis and apply findings in professional practice.

Conclusion

Doing motherhood activities is, on a practical level, moderately affected by the effects of inflammatory arthritis. Given the symptoms of this chronic disease, this finding is expected. However, being a mother was found to carry with it both a sense of strength and purpose which ultimately circumvented the negative effects of arthritis, illustrating the impact of positive occupational identity on the connectedness between doing and being a mother. Mothers in this study described inventive and resourceful accounts of nurturing, caring, and teaching their children as fulfilling, despite the interruptions on the cycle of doing and being by chronic disease. Participants saw themselves as the primary supporters and encouragers of their children within their communities; barriers to participation was not linked to how they saw themselves, but attributed to unrealistic expectations of others within certain settings.

More in-depth exploration of how doing and being support specific occupational roles or identities is warranted, with additional valued life roles and other populations. A person's belief in his or her capacity to maintain an important occupational identity, in this case as a mother, and the meaning ascribed to this occupational role appears to be more strongly supported when mothers see themselves as mothers, not as mothers with a disability. The meeting point for health professionals and clients seeking support for engaging in

life roles should be on the how they view themselves as occupational beings instead of the negative effects of their disability.

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CHAPTER 3

This chapter will expand upon what I learned about occupational identity and social context, particular to these women's experiences; reflexivity and the research process; and the practical implications of my research.

This narrative study explored the intersection of being mothers and doing motherhood activities in the presence of inflammatory arthritis. The storied experiences and daily lives of eight mothers were gained through interview, observation and a fine art exercise with accompanying descriptions. Following digitally recorded data collection, I utilized narrative analysis, which allowed full interviews to be transcribed and compared. These were then supported by data generated by myself, including field notes, analytical logs, and space/place diagrams. The resultant meta-narrative is my rendering of the stories told merged with a thoughtful comparison of related literature and discourse.

The research question, 'How is being a mother and doing motherhood activities affected by arthritis', is not a simple cause and effect experience. The main story line, "Just because I can't do, doesn't mean I'm not a mom" exemplifies the powerful connectedness between doing and being (Wilcock, 1998); I found doing motherhood activities and being a mother were inextricably connected. Participation, or 'doing', and identity, 'being' were maintained or disrupted by symptoms of a chronic disease; there is no resolution. The subplots of this story are participation (subplot 1) and fatigue (subplot 2). Participation emerged as a major subplot and described involvement in a life role and engagement with and for children. The main goal of mothers was to encourage and to be there for their children; this is how mothers enacted their roles and viewed participation. Fatigue emerged as the second subplot within the larger meta-story and universally disrupted participation and the cycle of doing and being. When interacting with others within community settings, two narratives represent differing level of inclusion within social contexts, which influenced social role experiences and participation: "They Just Don't Get It" and "The Motherhood Club".

Occupational Identity

The meta-story begins with stories that reflected motherhood versus stories of disability. Unexpectedly, the beginning of the meta-story related more to occupational identity, and less to having arthritis.

“I always wanted to be a mom” captures the initial and continuing thread of imagining, embracing and maintaining this occupational identity. Mothers preserved the identity of mother occurred primarily within the context of daily mother-child relationships, and secondly within certain settings in the mothers’ social and physical communities. Participants in this study relayed “I am a mom” despite challenges due to the unpredictable and sometimes unforeseen effects of inflammatory arthritis, such as overwhelming fatigue. As such, mothers identified themselves not only as engaging in the activities and occupations of motherhood, but also as occupational beings beyond the identification of ‘disabled’.

Mothers described the identity of mother first as imagined, then followed by an embracement of the right, joy and privilege to be mothers. Participants’ stories of parenting over time, such as “Watching her evolve has been amazing” and choosing to ignore other tasks to play with a preschooler, “We’re just going to have a day [together]” speak to the joys of being able to parent despite real limitations. Stories of stable, positive occupational identity allowed a positive view of self and parent-child engagement. Unruh (2004) asserts “More research is necessary to understand the way in which occupational identity evolves over the lifespan in response to life experiences” (p.294) which may include a crisis in occupational identity brought on by disability. Notably, my study captures how occupational identity can also be relatively static, thereby providing a secure grounding while balancing daily occupations and chronic disability; the need for permanence and stability in occupational identity was at the forefront of this meta-story.

During the research process, I considered mothers’ perspectives and allowed them to design their own stories of occupational identity. This aligns with a call to discover the positive and negative experiences and perspectives of occupational experiences (Arendell, 2000; Barker Dunbar & Roberts, 2006;

Brown & Williams, 1995) and brings the focal point away from the effects of arthritis, prevalent in professional literature, towards an understanding of how mothers see themselves as mothers and how they explain the effects of arthritis on their role. This was a stated objective of my study.

During the research process, I discovered asking about motherhood first may have uncovered a different perspective than asking about arthritis. In capturing the primary experience of being mothers instead of how disability affected mothering, the focus was changed. In qualitative interviewing, questions are changed depending on what the researcher has learned or has failed to learn (Rubin & Rubin, 1995). I found asking and probing about arthritis proved detrimental in allowing motherhood stories to emerge. The question asked of mothers crystallized during the research process to allow mothers to tell what they wished to have heard, from “How is doing motherhood things and being a mother affected by arthritis” to “What is it like to be a mother with arthritis”, and finally, “Tell me about being a mother.” When I encouraged participants to speak uninterrupted, they shared stories of their roles and valued activities, and then often followed with stories of how arthritis affected these roles and activities. These motherhood stories were unlike illness narratives, which are stories of understanding illness in everyday life (i.e., beliefs, effects of the disease, effects on daily life, and changes between the person, the illness and social identity) (Bury, 2001). Illness narratives were not paramount in reflecting accounts of affirmative occupational identity. Thus, the strength of how women saw themselves, versus how arthritis affected their roles, represented the pivotal beginning of the meta-narrative as well as a continuous influencing factor within the stories.

Being, Doing, and Belonging. Within the main storyline, “Just because I can’t do doesn’t mean I’m not a mom”, physical difficulties during active participation were common within some groups of stories told. Individual stories reflecting daily challenges included “Falling down, I can’t get up” and Cooking: “The same for everyone, but slightly more overwhelming for me”. I was told tales of not being able to ride bikes or play soccer; I found these stories scattered

throughout the transcripts. “The hardest part is the emotional part” reflects one mother’s worries of not being able to example an active lifestyle to her two energetic sons and worrying about the possibility of them “getting this disease”. One mother’s painting, a spiral of colors representing different activities and family members, is occasioned with red and yellow, which represented pain (red) and resultant ‘down time’, or inability to ‘do’ for and with her infant and adolescent daughter (yellow). Another mother, who saw herself as “the sporty one in the family”, conveyed that taking a “spectator” role was “tough”. However, mothers also reported that arthritis “...hasn’t gotten in the way” and “I’m part of it, but just not in the same way”. Amidst stories of ‘consequences’ or ‘losses’ in physical activities, mothers often alleged, represented by one participant’s story, “I’m not always able to do some things, but I make up for it”. I thought this was an important finding: constant alignment and identification with being mothers positively affected ‘doing’ motherhood things despite challenges due to the unpredictable and sometimes unanticipated effects of inflammatory arthritis. Mothers were less focused on being able to do activities with their children, and relied on being able to do what they could do: “...that’s just the way it is, it’s not an issue about what I can’t do, it’s just this is what I do do.”. Belief in do-ing, revealed through one process of narrative analysis as the repetitive words “I do” buoyed occupational identity. As such, doing motherhood activities and being a mother were found to be inextricably connected, reflecting the connection between being, doing, and belonging in occupational therapy literature (Wilcock, 1998). In related research, Dubouloz, Laporte, Hall, Ashe & Smith (2004) assert personal beliefs, values, feelings and knowledge (meaning perspectives) affect choice in daily activity (occupations) with people balancing inflammatory arthritis. My study found the meaning perspective of participants (belief in “I do”) buoyed participation in mothering activities despite the negative effects of arthritis.

My study also found that the goal of participating mothers was to encourage and support their children by being a consistent sustaining presence. Participation was not always linked to active performance, but involved activating and maintaining an identity as a mother; mothers stressed the unseen and

rewarding involvement in a life role. Mothers told me they often watched their children and provided verbal encouragement as they rode bikes or played soccer, and spoke of pride when their children independently undertook daily occupations, such as making themselves a sandwich. I learned these mothers utilized processes of being engaged with and for their children through strategies that worked around arthritis symptoms and aligned with their aspirations to be involved with and encourage their children.

This focus on involvement and encouragement was interesting as it seemed to circumvent the need for physical involvement, which, along with fatigue, was the most disruptive in day to day participation. This finding aligns with other studies that describe maternal involvement as focusing on supporting children's well-being (Barker Dunbar & Roberts, 2006), emphasizing caring and nurturing (Francis-Connolly, 2000) versus specific occupations and activities. From mothers' perspectives, engagement and support was seen as equally beneficial as doing things for their children, and again fed positively into occupational identity or 'being' mothers. This de-emphasis on active participation, or in this case, the shift in focus away from the ability to physically participate is an important finding. Previous literature identifies mothers with inflammatory arthritis face challenges in participation in household work and parenting activities (Backman, Kennedy, Chalmers & Singer, 2004; Backman, Del Fabro Smith, Smith, Montie & Suto, 2007; Barlow, Cullen, Foster, Harrison & Wade, 1999; Berson-Rosenthal, 1996; Grant, Foster, Wright, Barlow & Cullen, 2004; Katz, Pasch & Wong, 2003). My study begins to identify how mothers maintained their occupational identities despite challenges. This also supports Hammel's (2004) assertion that being able to 'do' in the areas of self-care, work and leisure is not necessarily the only way of seeking and experiencing purpose and quality of life. She emphasized that a sense of belonging points to the importance of relationships, connectedness, community, reciprocity, and contributing to others. The importance of relationships was shown through stories of time spent with their children and families and close circle of friends (those who "understand"). Connectedness was not necessarily described in the context

of feeling connected to others but reflected their connectedness to their identities as mothers, or “belonging” to the social role of mother. Additionally, when their community ‘allowed’ participation in ways adapted to their abilities, a sense of belonging occurred.

Participation itself included active observation, side-by-side activity, occupational scaffolding, learning for the future and adapting in the present. The latter two processes, titled ‘the learning game’ by one participant, exemplify how mothers framed participation optimistically: mothers presented themselves as learners and initiators; able to circumvent the “tricky” parts of parenting with arthritis using creative ways to participate that focused both on the needs of their children and their own needs and limits. This included “learning different coping mechanisms”; encouraging children to “do for themselves”, adopting relaxed schedules, involving others, adapting the way an activity was undertaken, or to be part of an activity in a different way by adapting their level or form of participation.

Opacich and Savage (2004) asserted that women with persistent illnesses are faced with challenges and choices in managing their own health and preserving the integrity of their families. Women in this study, while recounting the challenges, emphasized the benefits of choice, or “exercising options”. For one participant, choosing to hike one day with her children with a subsequent “rest day” was framed as a personal choice. Her children understood and adapted to the requirement of the “rest day” by choosing activities she could observe the following day. Another mother described monetary resources as choice-promoting, allowing gymnastics classes for her daughter. Asking for help was described as “calling in the cavalry” or “outsourcing” and seen as an affirmative versus negative choice. These findings support a stated ambition of my study, which was to report on the presence of positive adaptation. Measures are being developed to determine parents' perceived ability to control, or manage, aspects of their children's juvenile idiopathic arthritis (JIA) and the relationship to maternal well-being and maternal self-efficacy (Barlow, Wrights, Shaw, Luqmani & Wyness, 2002). A similar tool to measure how mothers

perceive being able to manage their arthritis and the varied roles of motherhood and the connection to maternal self-efficacy and well-being would be an additional perspective to consider further to the Parenting Disability Index, a scale designed by Katz et al. to describe parenting disability (primarily task related) with women with rheumatoid arthritis (2003).

A second interesting finding beyond the complexity of participation itself was the level of consideration, orchestration and re-patterning required preceding mothering occupations. As an occupational therapist that often assists clients in being able to 'do', I found this remarkable. Orchestration, including eight processes of planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting and meaning making (Larson, 2000), was weighted towards planning and balancing for participants in my study. Mothers considered the needs of their children and families, available support, the manifestations of energy and fatigue and asked themselves "What is expected of me?" and "What am I able to do today?" Planning for a day took time, energy and creativity; adjusting occupations based on what was expected and required on a given day. After searching for a term to describe this process, I settled on "Re-patterning," used in the nursing literature by Wuest (2000). Re-patterning is an apt term to positively label the multi-faceted processes of changing or adjusting occupations daily, if not hourly, to achieve a balance despite limitations of inflammatory arthritis. As well, mothers in this study shared stories of re-patterning and orchestrating their activities and the activities of their children to coincide with the available resources they had within themselves and their families. Contemplation and deliberation emerged as main processes preceding participation. Habitually, contemplation regarding the level of social acceptance from others (e.g., other mothers) the physical comfort of a setting (e.g., a school auditorium) the amount of time to be spent in a static position (e.g., sitting) and how participation would affect their ability to participate the next day with their children occurred. Mothers often referred to activities in the past, which one mother referred to as "try and succeed" or "try and fail" activities, to gauge how successful they may be in the current proposed activity. While mothers with a

disability have more difficulties in completing day to day parenting tasks when compared to women without chronic pain (Backman et al., 2007; Evans, Shipton & Keenan, 2005), women in this study shared stories which uncovered the deliberate, lengthy and occasionally overwhelming processes of re-patterning and orchestration that occurred preceding and in the midst of daily role-related tasks.

The impact of fatigue

Fatigue materialized as a major subplot, not for its presence alone but as a complicating or extenuating factor adversely affecting the cycle of doing, being and ultimately becoming. When looking at related literature, I found the mechanism by which fatigue interrupted the cycle of doing and being was a new finding. Fatigue prevented connection with other mothers in organized and unorganized events (volunteering/coffees out) as mothers were tentative about extending or accepting invitations. Mothers admitted to me this led to less connection over time. Within the larger community, fatigue precluded saying 'yes' to community social events, which again led to less invitations, and less interaction with other families and child-based organizations or events. This echoes findings by Brown & Williams (1995), who reported "One consequence of the unpredictable nature of the symptoms for the women in the study was that impromptu outings with friends had to be considered very carefully, or might be cancelled at the last minute...friendships waned when reciprocity was no longer possible" (p. 699). Another study (Plach, Heidrich & Waite, 2003) found women with rheumatoid arthritis described having positive interpersonal connections supported high social role quality. I would suggest that less connection may negatively impact occupational identity. Further, in examining the connection between doing, being and becoming, I hypothesize the interruption of fatigue may affect becoming mothers and feeling a sense of belonging to a maternal community, "the motherhood club" as one participant stated.

Fatigue was universally 'the biggest thing' or obstacle in daily parenting tasks for all participants, which I found agrees with current literature (Backman et

al., 2007; Grant et al., 2004; Grant, 2001; Katz et al., 2003). Mothers told me stories of not being able to cook large meals for family holidays and the necessity of going to bed when their children did due to “numbing” fatigue. Difficult decisions were made around being with friends and family who “got it”---the limitations caused by fatigue---and those who didn’t “get it”. Fatigue also prevented active participation, but mothers found a way around this by re-patterning activities and adapting (“I’m still part of it, but in a different way”). Interestingly, fatigue is measured presently primarily in terms of how it affects being able to do specific motherhood activities (i.e., Katz et al., 2003) versus how it affects social role quality and experiences.

Stories of Social Contexts: “They Just Don’t Get It” and the “Motherhood Club”

I discovered the major barrier to community participation from mothers’ viewpoints was the level of understanding they received from other mothers, teachers, children’s sport coaches, or service personnel (e.g.: a department or grocery store). If participants felt others saw them as physically normal, often unrealistic expectations occurred, including unattainable amounts of time or unfeasible physical involvement in volunteer positions in school, sport or extracurricular activities with their children. Understanding came from a few valued supports, often family members or close friends, who understood the limitations and unpredictability superimposed by chronic illness. A delicate balance existed between being able to say ‘I may need to cancel because I don’t have the energy’ or ‘this is what I am able to do’ and not volunteering altogether, which represents the juncture between subplot 2 (fatigue) and this story of context. Mothers in this study did not wish to be linked with other moms with arthritis per se, but to interact and be understood in their own community, and be able to suggest ways they could contribute. Mothers spoke of the invisibility of their illness as a contributing factor, and subsequent misunderstanding from others which in turn limited their participation. Mothers did not see themselves as disabled, consistent with other studies (Gordon, Feldman & Crose, 2001) or necessarily on a continuum of ‘normal’ as compared to other mothers (Farber,

2004) but 'just mothers'. Seeing themselves as 'just mothers' despite effects of arthritis on their everyday mothering occupations was based on their perception of identity versus what they could or could not do. If they had challenges, however, they wished others would "get it" and extend "a little bit of patience and understanding" when it came to navigating through a store or helping with a school art program. When they felt they could not provide the amount of participation expected, or they were misunderstood, they avoided these situations. Importantly, my study begins to describe the relationship between support and inclusion from within their community and the maintenance of occupational identity.

Learning about Research

Importance of Triangulation in Data Collection

During the process of utilizing all data to build a meta-story from the stories told, each data source provided different 'picture'; a unique contribution to the understanding of the mother's experiences. Each data source alone was not enough to fuel the process of analysis and subsequent creation of the meta-narrative. For example, during the fourth phase of analysis, the research question was asked of each central story: principal stories chosen for their representativeness, completeness and coherence. My observation notes, interview transcripts, reflexive notes, field notes, art and art narratives were drawn upon to support or refute these central stories and thus were vital for the development of a meta-narrative. The document review and participant observation, in particular, assisted me with understanding the importance of environmental and social context, as well as mother's perception of how arthritis has affected them in their occupations. During a walk with one of the participants with an infant in a stroller, I noted how difficult it was for her to physically handle a stroller and walk three blocks. When she asked me for assistance in getting the stroller over a curb so she would not spill her coffee, I could understand why she said she was hesitant to call "a friend for coffee." In addition to needing

assistance over curbs, she walked very slowly and felt she could only do this activity on a 'good day', something she felt another mother may not understand. Another example of a mother of an adolescent girl acutely stressed the subtle equilibrium of being able to walk together during one of my observation times with this family: her young daughter, initially wishing she had stayed home, impatiently ran ahead of us with a friend and played Frisbee saying to her mother, "Well, you run then". Arthritis had disrupted, but not eradicated, their ability to walk together at the same pace. A further example was the small painting that each mother produced during the last visit. Initially, a half hour was thought to be sufficient time for this activity, but after engaging in this exercise with the first two participants, mothers asked me for more time to produce a painting they were content with. The interactions during the exercise, as well as the resultant descriptions of the art pieces are summative and capture the mother's full understanding of what it means to be a mother living with arthritis (Appendix E). Drawings are both a visual product and a process in which people can come to understand illness conditions (Guillemin, 2004), however, I discovered this data collection method served as a method of self-expression, and brought closure to the research process for the mother and myself, the researcher. Most importantly, the stories about the paintings were positive, self-directed and insightful; illuminating what was important and valued instead of what is difficult and challenging.

Accounting for Presence of Self

My own experience as a researcher, and how 'self' was a significant influence in the process of inquiry was addressed through a reflexive process and recorded in a research log. My motives and feelings during the research process were undoubtedly swayed by being a mother and an occupational therapist. In the latter role, reflecting on my motives, training, biases and methods of approaching clients in a clinical setting resulted in efforts to 'unlearn' the clinical interview (Ely et al, 1991) and allow a storied interview to take place. This included becoming comfortable with pauses, silences, long chronicles and

scattered stories versus guiding a time-limited question and answer exchange. In the 'mother' role, I recorded how being a mother somewhat determined how I felt I was viewed by the participants as an 'insider'. I noted participants may have told stories to a 'mother/researcher' rather than a 'researcher', which in turn flagged me to encourage more details if mothers left some things to the imagination because they may think that I 'knew how it was' so to say. This was assisted by specific analysis processes such as locating word repetition, emphasis and placement. One mother, when thinking of certain instances when she was particularly challenged in daily mothering occupations because of the severity of her arthritis symptoms, frequently said "you know" after many sentences. Locating word use, the use of extensive field notes as well as reflecting on my researcher role allowed for an interpretation and an awareness of how 'self' affected the process.

Wendy Sword (1999) suggests two areas to address in the reflexive process that are relevant to me: managing my role and strategies to make meaning from gathered data. In retrospect, maintaining a research log assisted greatly assisted in the process of reflexivity. As a mother, the demands of doing research were sometimes overwhelming:

On being a mother researcher...OK: pain, agony, guilt, sadness, feeling like I'm missing out—co-habitates with pride, a sense of accomplishment in what I do when I'm away from them and hoping they will also be proud of me...are they are too little to have crisp, fresh memories of 'mommy in school' with associated feelings [sad? bewildered?] ---maybe not. Trying to get good food into them, love them, do their laundry and try my best to separate my work life from my home life, because I feel like if I allow the two worlds to meld I won't be the 'good mother', now, that is interesting. What is a good mother?

Feeling torn between two worlds certainly had an impact on how approachable I might have been during an interview; I wondered if the participants I visited may have sensed I was distractible. A solution to this was to take up offers of engaging in conversations about motherhood experiences of the day (toilet

training, late bedtimes) to clear the slate for more involved conversations stemming from the research question. In the short time I spent with mothers, these shared stories definitely shaped our relationship. Communication through e-mail during the member checking process was again marked by sharing motherhood trials and tribulations. Indeed, as I recently sent each mother a synopsis of the research findings, I decided to attach a cover letter attributing the delay in my communication to the arrival of my infant son together with an embedded photograph.

Making meaning of the data, particularly thinking of present research findings and their relationship to this study, was somewhat opaque and bewildering until the latter part of the research process. Advised to compare my findings to current research when all of the individual stories had been analyzed, much time was spent in a frustrating state of 'analysis-paralysis.' I partly attribute this from feeling torn between the worlds of 'mother' and 'researcher', which affected how quickly it took to immerse my intellect during the complex analysis process. When comparison occurred in the end stages of analysis with help from a peer researcher, a sense of purpose and certainty ensured, captured in this excerpt of the research log:

Starting to think about orchestration and re-patterning. The choices these moms make are complex and every day activities have to be measured against level of interest, physical ability to participate, what others may do to help or not, etc. Participation becomes thoughtful. As one mom said, it's not like she can just get up and say, "OK, Let's go!". So how these moms feel they are 'seen' when they do go out, affects if they go out, and how. Re-patterning participation is high based on measuring the benefit: socially, spiritually, physically, and emotionally. Activities are "plotted", and mothers measuring the risk as well as the level of benefit to their children.

Thus, the reflexive process not only perpetuates the researcher's awareness of her role in the research process, but also facilitates 'doing' research by making clear the researcher's challenges and feelings toward the data as influenced by

their own standpoint, goals and motives. Most importantly, one product of reflexivity is the awareness of being 'stuck' in the quagmire of a multitude of competing research processes. In this case, an awareness of my tendency to over analyze and not miss important data led to seeking guidance; when challenges seemed insurmountable, guidance lent objectivity to the results of my researcher tendencies and ultimately became one strategy to allow making meaning of the gathered data.

As a mother and an occupational therapist, the reflexive process also enhanced my understanding of how I interpreted the data. Early in the research, I was struck with how motherhood stories, versus arthritis stories, permeated each mother's account. Being a mother led me to be sensitive to these stories and I saw the beginning of the meta-story, "I always wanted to be a mom", emerge as an important finding. While I felt mothers were consistently relaying the importance of this anticipated and acquired role, my interpretation in part can be attributed to my role of mother of three children. Another researcher might have not interpreted the data in the same fashion. As an occupational therapist, looking at the cycle of doing and being led me to recognize specific theories and views on occupation, disability, and meaning. The interplay of doing, being and belonging is one example (Wilcock, 1998). Reflexivity influenced both my interpretation and awareness of the data. Peer and member checking allowed verification of how I placed importance on certain findings.

With regard to the three stated study objectives, stories of mothers' experiences of nurturing, teaching and caring for their children were interwoven throughout the findings when they were utilized to describe participation and fatigue, the two subplots. Participants understood and explained the effect of arthritis on their role of mother on a continuum of 'it makes it different for me' to 'it doesn't effect how I mother; I'm just like any other mom'. This understanding did not change how they perceived themselves as mothers, and did not appear to limit how they saw themselves as participating within their motherhood role. However, mothers universally described how other's perceptions of them changed the way they participated in child-driven activities and social time with

other mothers and in volunteer opportunities within their communities. As the researcher's responsibility is to reflect what is told, not what is sought out in the onset of the study, the difference in alignment to study objectives is expected.

Implications for Practice

This small study is important because it captures the relationship between doing, being and becoming in the presence of chronic disease in mothers. It contributes to new knowledge; participation was framed by participants in this study as engagement in a life role through support and encouragement of their children secondary to participation in specific activities of work, self-care and leisure. For the mothers I interviewed, engagement in the role of mother, often without overt occupational performance, was just as meaningful to the fulfillment of occupational identity as the ability to freely actively participate in everyday occupations. Conversely, models of occupational performance, such as the Person-Environment-Occupation (PEO) Model (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996), focus on the fit between the person, the environment and the occupations engaged in as a determinant of the quality of a person's experience with regard to their level of satisfaction and functioning. The PEO model begins by assessing occupational performance strengths and difficulties (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999). When performance in occupation, activities and tasks is seen as secondary to 'being', occupational therapists may wish to consider the possible mediating effects of positive occupational identity when occupations themselves are balanced with a chronic illness. Indeed, if our main goal as successful therapists is to "... enable the individual with a disability to be as functional as possible" (Stein, 2008) my study illuminates the need to look at other determinants of the quality of a person's experience based on other factors such as self-identity, positive role experience and occupational identity. Practically, occupational therapists should actively look for these determinants within client's stories, and develop treatment plans that

focus on how mothers can support and encourage their children through 'just being there.'

I focused on listening to and allowing full stories to be told, consistent with the qualitative line of inquiry called narrativity (Frank, 2000). Listening to silences, omissions and allowing participants to fully story their experiences could be valuable with other research questions in areas where little is known about a human experience. Occupational therapists are well-suited to utilize this line of inquiry, as listening to a person's daily experiences in productivity, self-care and leisure is often the beginning of building a therapeutic relationship towards achieving goals in the 'everyday'. As such, occupational therapists should be encouraged to consider narrativity to answer questions arising from clinical work. One of the most compelling tales of being a woman with arthritis is captured in a novel by Mary Lowenthal Feistiner. Published in 2005, Out of Joint: A Private and Public Story of Arthritis tells a complex story of her own experience of a 'socially hidden' disease, how it impacts her as a woman and a mother and her opinion of how medical research has progressed thus far. As narrativity encourages listening to one's whole story, becoming familiar with stories about living with arthritis or other chronic illnesses may promote developing a 'listening ear'.

As this study found that orchestrating occupations was taxing due to the lengthy consideration process (of deciding whether or not, when and how an occupation could be pursued), enabling mothers in the planning, forecasting and anticipation of mothering tasks may be just as helpful as dealing with the effects of the disability itself. Secondly, I found mothers in this study were profoundly creative and resourceful in orchestrating motherhood occupations despite, and sometimes because of, fatigue and physical limitations. Building on each client's strengths and resources may positively affect everyday participation and self-identity.

Fatigue emerged as a major subplot in this study, both interrupting the cycle of doing, being and becoming and as a barrier to participation. Measuring fatigue in terms of how it affects being able to do specific motherhood activities as well as how it affects social role quality and experiences is a future

consideration. Asking about the limitations of fatigue in the context of daily occupations is important, not just how much fatigue is present. Occupational therapists could assist mothers to manage fatigue by encouraging them to be realistic and comfortable re-patterning activities within the contexts of their family life, as well as assisting them to develop clear communication with family members and others when expectations exceed energy levels.

It may also be important to focus on the connectedness between doing and being and the possible interruption by chronic disease. Mothers in this study saw themselves as mothers, not as mothers with a disability; focus on this role and the meaning it gave renews the positive, instead of the negative effects of disability.

In summary, the strengths of this study include verification and reflexivity strategies to ensure trustworthiness. A limitation in data gathering was the short time between meetings with half of the participants. This might have not allowed all mothers equal opportunities to story their experiences. This study should not be generalized to a larger population, as with similar qualitative studies, but provides a unique opportunity to understand the mothering experiences of married women with inflammatory arthritis with children fourteen years and younger who are married or partnered. This study may have been strengthened by the addition of mothers from different ethnic and cultural backgrounds as well as mothers who are single or have same-sex partners.

Conclusion

This study described how mothers with arthritis experience mothering in the presence of arthritis, and how this experience affects participation, social interaction and self-perception. Participants in this study demonstrated confidence through elements in their stories that they were primarily mothers despite the daily challenges of IA. This confidence and knowledge in being mothers, or 'I am a mother', exemplified the potency of strong occupational identity in the face of chronic illness. Belief in doing and knowledge in being

mothers equalized many of the disruptive effects of inflammatory arthritis. Mothers described opportunities for learning and adapting to the caring, nurturing and teaching aspects of motherhood despite the sometimes unavoidable manifestations of arthritis. Positive belief in being mothers enabled participation, often in a different way than they had imagined. The many processes of re-patterning and orchestration became integral to encouraging and being there for their children. Inclusion into the motherhood community at large through acceptance of this diverse type of participation could enable the mothers' positive experience of 'being' mothers and thus positively impact the interrelated cycle of doing, being and becoming. This, in turn, may allow mothers to be what they envision themselves to be.

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APPENDICES

Appendix A: UBC Behavioral Research Ethics Board Certificate of Approval



Certificate of Approval

PRINCIPAL INVESTIGATOR Backman, C.L.		DEPARTMENT Rehabilitation Sciences	NUMBER B06-0333
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT Vancouver General Hospital ,			
CO-INVESTIGATORS: Chalmers, Andrew, Medicine; Del Fabro Smith, Linda, Rehabilitation Sciences; Suto, Melinda, Rehabilitation Sciences			
SPONSORING AGENCIES Canadian Arthritis Network			
TITLE: Mothers with Arthritis: Experiences in the Stories of Mothering			
APPROVAL DATE 06-05-11 <small>(yr/mo/day)</small>	TERM (YEARS) 1	AMENDMENT: July 1, 2006, Advertisement / July 13, 2006, Recruitment letter / July 14, 2006, Recruitment method	AMENDMENT APPROVED: JUL 25 2006
CERTIFICATION: <p>The request for continuing review of an amendment to the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <p style="text-align: center;"><i>Approved on behalf of the Behavioural Research Ethics Board</i> <i>by one of the following:</i> Dr. Peter Suedfeld, Chair, Dr. Susan Rowley, Associate Chair Dr. Jim Rupert, Associate Chair Dr. Arminee Kazanjian, Associate Chair</p> <p>This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p>			

Appendix B

Consent form

THE UNIVERSITY OF BRITISH COLUMBIA



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Mothers with Arthritis: Experiences in the Stories of Mothering

University of British Columbia, Vancouver, British Columbia

CONSENT TO PARTICIPATE IN RESEARCH

Student Investigator: Linda Del Fabro Smith, BSc. OT, MSc. Student, School of Rehabilitation Sciences
Email: delsmith@shaw.ca Tel: 604-871-4564

PURPOSE OF THE STUDY

The purpose of this study is to understand how mothers with arthritis experience being a mother in the presence of arthritis. By understanding the experiences of mothers who have arthritis and do motherhood activities, health professionals can learn from their experience and better serve mother's needs in the community. You have been asked to participate because you are a mother living with inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, or lupus) with at least one child (0-25 years) living at home. Your participation in this research study is voluntary. You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. This study has been awarded a graduate student fellowship through the School of Rehabilitation Sciences, and a graduate student award through the Canadian Arthritis Network. This study is the basis for a graduate thesis.

PROCEDURES

If you volunteer to participate in this study, you will be interviewed and observed by Linda Del Fabro Smith. Your participation in the research may help other mothers and professionals understand what it is like to be a mother in the presence of arthritis. You will not directly benefit from your participation in the research. You will be asked to consent to:

1) Participate in two interviews, spaced approximately two weeks apart. Each interview will be about 45-90 minutes long. The interviews will take place in a setting that is convenient to you, such as in your home or in a coffee shop. The interviews will be audio recorded and typed up by the researcher.

- 2) Allow the researcher to visit you in your home in an everyday activity, such as mealtime or during one of your children's leisure activities. This will take approximately 3-4 hours. The researcher will take notes during this observation period.
- 3) Write in a journal (diary) your thoughts about being a mother with arthritis, and share this with the researcher. The amount you write is completely up to you. You will be provided with a notebook. You will be provided with a photocopy of your journal notes.
- 4) Optional activity: During the second interview, paint a simple picture that will help the researcher understand the impact arthritis has on your life. You will be asked to explain the painting to the researcher, and you will be provided with a photocopy of this picture. If you agree to participate, you will allow the researcher to retain and use the painting and excerpts from your story when she makes public what she has found out about how arthritis affects motherhood activities.

POTENTIAL RISKS AND DISCOMFORTS

There are no obvious risks associated with the interview or observation time. Talking about the how arthritis affects your life as a mother may be emotional. There is a total time commitment of about 5-7 hours over a two to three week period. Having someone observe you in your home may be awkward. If you are experiencing any of these, you can tell the researcher at any time. You can stop a session at any time with no consequences to you or your family. There is no unforeseen conflict of interest on the part of the student researcher in this study.

COMPENSATION

You will receive no payment for participation. You will, however, be offered a small \$25 gift certificate in recognition for your time.

CONFIDENTIALITY

Your identity will be kept confidential. Any personal information that is recorded in connection with this study will be removed, and a code will be used instead. Only the researcher will be able to break that code. A code will be used on the transcribed audio interviews, the observation notes written by the researcher, your journal entries, and the painting (the research materials). Computers used for transcribing information are password protected, and the password is only known to Linda and her thesis supervisor, Dr. Catherine Backman. Your name will not be used in any presentation or publication of the study results. If Linda quotes any statements from your interview, observation time or journal, they will be identifies by a pseudonym (not your real name). All of the research materials will be kept in a locked filing cabinet at the Arthritis Research Centre of Canada. The researcher and her thesis committee will have access to this data. If you have any concerns about your treatment or rights as a research subject, you may telephone the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at 604-822-8598.

IDENTIFICATION OF INVESTIGATORS

Linda's thesis committee, who are responsible for overseeing the project, are Dr. Catherine Backman, Dr. A. Chalmers, and Dr. Melinda Suto.

If you have any questions or concerns about the research, please feel free to contact:

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SIGNATURE OF RESEARCH SUBJECT

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Subject (printed)

Signature of Subject

Date

Appendix C

Detailed data collection and management

Data was collected by the researcher included in-depth un-structured interviews, general demographic questions, participant/family observation, document review and a fine arts exercise (painting a simple picture) by the principal investigator. Data collection took place in the participant's home and community from June, 2006 to October, 2006. Ethical approval was given through the Behavioral Research Board of the University of British Columbia (Appendix H), Vancouver, British Columbia. Participants signed a consent form before the first interview and were provided with a copy.

Two interviews were conducted with each participant, before and after the participant observation period; each participant therefore had 3 visits from the researcher. The exception to this was during an out of town trip. Four participants were seen in two sessions: the first interview, followed by a second interview/art exercise/observation period. The length of time between interviews ranged from one day to one month. This was based on the available time the participant could offer the researcher, and the researcher's schedule. Often, observation periods were re-scheduled due to illness or conflicting schedules, such as children's activities.

The aim of the interviews was to understand what meaning is given mothering and mother's perceptions of how they participate in mothering with the presence of arthritis. For the first interview, lasting 45-90 minutes, a guide was used to cue the interviewer to topic areas to be covered (See Appendix B). The primary question asked of each mother was "Can you tell me what it is like to be a mother living with arthritis?" Participants were encouraged to speak uninterrupted as they told their stories. At times, prompts such as "What did you mean by that?" and "Can you give me an example?" encouraged them to expand on their stories.

Areas to explore during the second interview were driven by the participant and the researcher. When a participant seemed to indicate importance by

stressing parts of their story, or when there was a pattern of omission, this was recorded during the interview. Together with small phrases representing areas of interest to the interviewer, areas of future exploration were jotted down during the first interview. Questions coming from these notes were asked during the second interview. The aim of the second interview (20-30 minutes) was to clarify questions the researcher wrote down during the first interview or the participant observation time, and allow the participant to add to or elaborate on anything they felt was important. The primary question asked of the interviewee was "You have had some time to consider being a mother with arthritis. Is there anything you would like to add?" The two separate interviews were digitally recorded. Field notes were recorded directly after both interviews.

During the first interview, mothers selected an everyday activity for participant observation, which was scheduled for another visit. Activities were "everyday" activities, and included meal times, children's sporting events, playtime, dog walks, walks outside with a stroller and driving to and from school. The aim of participant observation was to explore the different aspects of the mother's lives including planning and engaging in mothering tasks. Document review included looking at photo albums, family pictures, and children's school documents such as art projects. The aim of document review is to allow mothers another way to understand and explain the effect of arthritis on their roles.

Mothers were also asked to keep a reflective journal between the two planned visits, however, this activity was described as being too time-intensive by the first two mothers and was set aside early in the research process.

The document review and participant observation assisted with understanding the importance of environmental and social context, as well as mother's perception of how arthritis has affected them over time in their occupations. The investigator kept a journal and multiple recordings of observations (field notes) and endeavored to record impressions, questions, observations about the setting, the mood of the interview and observation times, and began to ask questions about the data immediately after visits. This was an integral beginning step of data analysis.

Finally, participants were asked to do a painting, using acrylic paints, 8 1/2 by 11" sheet of paper or canvas. Mothers were given all materials necessary and all the time they wished to paint a simple picture in response to the question, "What are the most important things about being a mother?" This was undertaken during the last visit. Initially, a half hour was thought to be sufficient time for this activity, but after engaging in this exercise with the first two participants, the mothers wanted more time to produce a painting they were contented with. Drawings are both a visual product and a process in which people can come to understand illness conditions (Guillemin, 2004) in qualitative research methodology. Artistic endeavors used in therapeutic settings may provide a "...visible record of achievement...strengthening self awareness and self esteem through enabling self-expression..." (Reynolds & Prior, 2003 p. 786). This exercise also served to bring closure to the research process for the mother and the researcher, and end the time spent with the researcher on a positive note by asking about what is important and valued instead of what is difficult and challenging.

These forms of data collection were used with all 8 participants until data saturation was reached within each participant, as determined by the principal researcher, her thesis committee and one peer reviewer. Participants were thanked by card and given a small (\$25.00) gift certificate during the last visit.

Five approaches addressed rigor in the data collection stage: Collaboration with the Consumer Advisory Board at the Arthritis Research Centre of Canada, collaboration with one qualitative student-researcher in the field (peer review), consultation with the researcher's thesis supervisor and thesis committee, and reviewing the findings of the first interview and observations with each participant during the second interview (member checking).

Data management, including most transcription, storage, and mailings, were done by the principal researcher. Data was recorded digitally, downloaded onto CD and stored in a locked file cabinet. Data included transcripts, field notes, analytical memos, correspondence, the completed paintings, and the memory chips housing the interviews. With the exception of four first interviews, all data

was transcribed verbatim by the researcher (interviews, all second interviews, observation notes, reflexive notes, field notes, and the explanations of the content of the art exercise). Recordings were listened to and simultaneously compared to transcribed manuscripts at least twice for accuracy.

Appendix D

Interview guide

Primary question: Can you tell me what it is like to be a mother living with arthritis?

Follow-up questions

Can you tell me that it's like to be a mother?

What does motherhood mean to you?

What are the most important things about being a mother?

How does arthritis affect this?

What are the things (tasks) that are affected by arthritis?

What parts of motherhood are difficult for you?

What are the things about you as a person, the things you value, that are affected by arthritis?

How do you see yourself as a mother?

How does arthritis create problems in being a mother? How does arthritis affect the things you do as a mother?

Cues and prompts

Can you tell me more about that?

Can you give me an example?

Earlier on, you said _____. Can you tell me more about that?

Earlier on, you said _____. Can you describe how this made you feel?

Can you expand on that for me?

I was really interested in your comment about _____. Can you describe that more for me?

Appendix E

Participant's artwork and participant's art explanations

Participant 1

E.1



I: Can you just tell me about that.

P: Well, it's just the hands of my three kids and myself, basically that we are all connected, all joined I guess with me the mom being the focal point and the kids are all together, my hand fits on top sort of the basis, the grounding, the keeping them together, the anchor guess I guess there is not anything else to it.

I: You were saying about the handprint there, you couldn't get it down..?

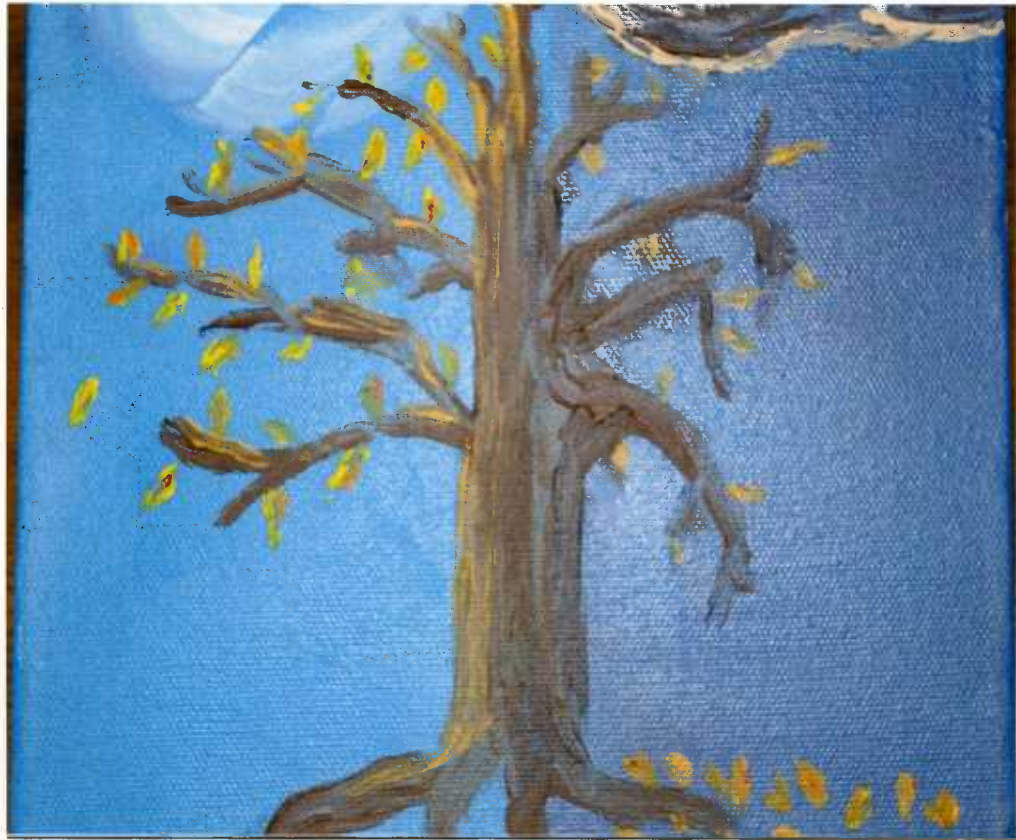
P: Yeah, that's because of the arthritis, it won't let my hand go flat anymore so...and that would be it, a great big hole in the middle (laughing) but yeah, it's because of the arthritis. It would have been nicer if it had gone flat, it would have shown more connection, more anchoring and drawing in. Because my fingertips and touching everybody's, everyone's handprints. It's kind of neat that the older

brother, with the younger siblings they are touching his but he's not...it's kind of neat 'cause older kids tend to be a grounding force as well.

I: I like it.

Participant 2

E.2



I decided to—I started painting blue, and then I thought that I would do the good side and the bad side and so then I had to paint one side darker. Then looking outside the window I saw a tree, that's where I got that image. But in my painting, ah—the bright side is the motherhood side, because there are so many positive wonderful things about being a mother. I guess there are awful things too [laughing] this tree could be the good and the bad of motherhood too. But what I was thinking you know, just about---how it just gives you a lot of life to be around kids and things like that. And I guess the tree was a good image because I feel like I am the tree of the family, where I support the family, and things just wouldn't be the same without me, I'm—you know, husband is great but he's not—you know, I kind of---it sounds goofy, but I kind of tell him what to do, he waits for—well, this needs to be done, OK, whatever, but I'm the one that's sort of---I plan everything, he doesn't plan vacations, it's me, and it always has been, you know.

And so the leaves on the motherhood side are a little brighter and fresher. And the ones on the arthritis side are kind of tired and dormant, because they need to go to sleep down at the bottom. And ah—it's—although it didn't do anything for the picture, I put a silver lining on the clouds on the arthritis side, because there are positive things, it's not all bad, you know, for me, I'm at home with my kids, and that's—you know, it's a definite plus. And also—I didn't show this on the picture, actually, it's almost opposite, it's—I am less stressed. Working and being so tight in that rat race it takes its toll, and I'm just way more relaxed. It's just easier to say, oh well, you know, things that—waiting in a line up at the grocery store, I would be looking at my watch, and thinking, Oh my God, I've got things to do, and now I can just stand there. You know, people are apologizing that they are taking so long, and it's like, It's ok, things—I mean I do have times when I am in a hurry, I'm late way more now than I used to be, it's—I'm just way more relaxed, it's not something I'm really proud of, being late, it happens. In the picture it shows the branches being sort of tired and broken, which is what my limbs feel like. But ah—there was something—that I started on before; maybe they should be stronger but—Oh I know, stress. Maybe the branches on the other side should be showing some stress. Didn't really—well, except the other side is motherhood. I'm confusing myself. Um—motherhood is stressful. The roots are a bit stronger on the motherhood side, the arthritis side I don't feel as stable. I don't know. That's kind of all there is.

I: It's great.

Participant 3

E.3



I: Can you and your mommy tell me about this painting?

[son]: Yeah!

P: Well, it's supposed to be kind of like a pie, you've got your house—we spend a lot of time in the house and in the car [laughing] and then at church, the baseball diamond, it's supposed to be a bat and a ball—and reading, because I like to read and drink my tea. And of course, it is very appropriate that [son] has painted everywhere because he's everywhere—doing everything with me. [to son] Right? Even when we paint at home, he still paints on my picture [laughing]. We print one out for me at home but what's the use, they're not mine!

[Son]: And Daddy can paint mine! And I can paint Daddy's!

P: We paint everyone's, right? We share.

I: So what do you want this to tell me about you being a mom?

P: I'm busy! [laughing]. I don't know. Ah—well, I guess that [son] is everywhere, and I love that. It doesn't matter that he's painted on it because I love spending time with him.



Well, what did I--because it is supposed to be about being a mother and so I thought I would draw a painting of the family, and at first I just thought I would do the family, and faces—I'm not good at faces so I didn't draw faces. And I um---at first when I did it the hands were not touching, but we always hold hands so I wanted to show that---us all holding hands, because one thing I enjoy every day about being a mom is being able to hold hands with my kids. Like today [daughter] was running ahead of me coming home, and I said, 'Why don't you just walk with me and hold my hand?' [laughing] Anyway, and we're outside a lot, we like hiking and walking and that kind of stuff—and even just here, because we are always outside, so I thought I would make an outside scene and um---as far as how it reflects on my arthritis, I'm really not too sure, except for my family has always been supportive of me and helpful, and [husband] has been so---sort of showing us all together shows how my family has helped me with that.

I: Is that the sun in the corner?

P: Yeah, it's sort of a bad sun [husband, participant and researcher laugh].

Participant 5

E.5



I: This is the art exercise for participant number 5. Tell me about your painting.

P: Well, in the four corners there are four circles of color. The light pink represents B, my eight month old daughter, the light blue represents M, my ten year old daughter who has never really been a pink person, the darker blue represents me, and the green represents my husband, that's his favorite color. And there is a light green. So there is kind of a swirl that's meant to be my day, not really a swirl; kind of off centered really. And the beginning of my day starts with a long period of peace, just waking up. And there is a red piece—red represents pain and my color is mixed in with the red. And it goes on to the light blue, which is my daughter M., I wake her up and then B. is awake. We kind of spend the morning together getting her ready for school. And then B. and I have a time, we sleep; and then my husband comes home, and we kind of start our day and it's a busy—my husband and I and then there is some yellows, and it gets brighter as the day gets busier. And then the red represents pain. I'll have pain at the end of my busyness, and then the light blue represents picking M. up from

school, and we almost always do that together. And so there is me, and my husband and B. And then we come home and we usually have a down time, so there is a nice little calm period. And then the busyness of homework and supper, and then M. goes to bed first, then my husband usually tucks her in, and then I'll tuck her in, and then my husband and I spend some time with B. And then B. goes to bed. Right before bed we watch TV or whatever. And I have pain. Then I go back to my calm. And it's kind of circles, I don't know why I chose circles, I think maybe because we are a well rounded family, we kind of all meld in together. I think that's it.

Participant 6

E.6



I: Can you tell me about your painting?

P: Oh, I have to tell you about it! [laughing] The hard part was painting it, this might be harder! Um—well, I put the sunshine because I always feel so good when the sun it out, and I don't know if that's a mind over matter thing, but I enjoy the sunshine a lot, and the rainbow—the rainbow kind of looks like a slide, and I guess that is to say that sometimes things are up and sometimes things are down, but I—I like to think that I keep myself on the curve of the rainbow, so that I'm not too—you know, feeling super super good or super super bad but try to keep myself in the middle, I guess. And the hand is—the hand is for so many things, the hand is for being a mother 'cause—I don't know, I know there are people that can't use their hands and they are mothers, and I don't know how they do it. Cause for me, the hand is so much a key part

of me and being a mother, it gives everything; it gives discipline, it gives love, it gives encouragement but also the hand symbolizes the arthritis now too—

[daughter]: And the hand is for picking up things too—

P: And the heart is for the love in the palm of my hand, I just feel like that goes straight through your arm into your heart and—and so it all kind of joins together that way. I: It's great, I like it.

Participant 7

E.7



I: Tell me about your art.

P: Um, my art—this is N's heart [daughter] and so I just want her to have—to be happy and this painting makes me happy, so I think of her being happy here. Happy heart, and that's the most important thing to me, and my wish for N is for her to be happy in her life [crying] no matter what she does. Whether she's a doctor [daughter slips beside mother and embraces her] doesn't matter to me, just—to be happy and to remember that the cup is always half full, not half empty.

[Daughter]: I love you.

P: I love you too.

Participant 8

E.8



I: So now you have to tell me about your painting.

P: Tell you about my painting [laughing]—

I: What you were thinking about when you were doing it, what it is all about—

P: I was thinking about my garden, and that it is really where I like to be and um---my rock wall because I started doing a rock wall, but it is not really a fun thing to do. So it's about this tall. And I was going to paint a window frame but I decided I didn't want to afterwards—it was going to be looking out on it. I like going out into my garden to relax, and I have a hammock that's out there. And the boys—they don't like helping me but they like to ask questions about the flowers and they like to be out there and enjoy the sun. That's kind of one of the things that we do that is special. So. And my gate, because I always said I was going to have a gate that didn't have a fence [laughing] and see how many people use the gate. But yeah, I don't do well with putting thoughts out like that!

Appendix F

Art exercise observations

A few interesting observations came to light while watching the mothers during the process, ranging from trepidation when first introduced to the activity, to pride upon completion. At first, mothers were daunted by the request and common responses ranged from “I’m not too sure what I’ll be doing here” and “I’m not really an artist!”. Upon some encouragement, mothers found ways to both engage their children in the process by allowing them to contribute ideas and, in some cases, assist in the actual painting. Children drew near to their mothers and became active participants, and were seen verbally encouraging their mothers to continue. In some cases, children wanted to do a painting as well, and they also painted while their mothers did. Playful teasing, asking questions about the content, and observation was seen on the children’s part during the activity. If the children were playing in another room, they frequently returned to see their mother’s progress. As mothers worked on this activity, the common finding was intensity and dedication to the final product. Mothers moved along a continuum of sorts, beginning with initial wariness to full participation and finally ownership, with subsequent pride (smiles, relaxed postures, and comments such as ‘I’m happy with it’) which seemed to express interest and engagement. Mothers asked to sign their art and gave very eloquent descriptions of the content of their work.

Appendix G

Detailed Data analysis plan

Step	Process
Read each interview	All interviews and subsequent transcripts were read and re-read with focus on how words were used in text.
Develop facts chart	Each participant's facts chart included: participant, age, number of children, paid/unpaid work, number of years married, diagnosis, key phrases about motherhood (caring, nurturing, teaching, protecting) key phrases about motherhood role is affected by arthritis, key phrase about how participation (home/community). (Sandelowski, 1995)
Develop story summary	Written summary produced of each participant's entire interview; verbatim as much as possible
Identify parts of interviews for analysis	Identifying excerpts by hand included: <ol style="list-style-type: none"> 1) motherhood activities ('doing'), 2) identity phrases: 'being' a mother, 3) Experiences of nurturing, teaching and caring for children, 4) Explanations of how arthritis affects their role of mother 5) Explanations of mothers understand the effect of arthritis on their role of mother 6) Explanations of participation in community: within family/outside of family <p>These parts were labeled "edited"</p>

Step	Process
	version for narrative analysis”
Identify /grouping told stories	The edited version for narrative analysis transcript was divided into 3-5 sections for each participant. These sections were labeled ‘told’ stories, and titled using the participant’s words.
Identify 2-3 central stories per participant	<p>Two or three were chosen from each participant from told stories as they</p> <ol style="list-style-type: none"> 1) contained all elements and mirrored, in form and function, <i>all</i> told stories, 2) were central to either ‘doing’ motherhood activities or ‘being’ a mother, 3) contained full, detailed descriptions, and 4) could be rigorously analyzed using a data analysis plan. 5) were a good representation of my understanding of the participant (my experience of them and my sense of the whole person):which stories were able to represent the person as I knew them 6) Impact: Complete stories versus chronicles or answers to questions, had potential to speak to the research question <p>From these stories, labeled ‘central’ stories, both positive and negative experiences were represented Common themes/ alternative perspective (including outliers) were identified</p>

Step	Process
Identify narrative forms and functions in each central story	<p>Narrative forms and functions included:</p> <ol style="list-style-type: none"> 1) Key events 2) Key turning points 3) Key actors 4) What the story revealed about the individuals circumstance 5) How the story was told 6) How past/present experiences were contrasted 7) How the effects of arthritis on mothering was discussed 8) Vocabularies used (striking, standing out) 9) How tensions were expressed in communication/topic 10) Identifying stories such as moral fables, success stories or failures 11) Character portrayal 12) Vocabularies/rhetorical devices (Coffey and Atkinson, 1996) 13) Key metaphors 14) Key words 15) Verb tense 16) Other linguistic choices and how substantive themes are developed through these (Reissman, 1993) 17) Universal story structures such as tragedy, comedy, satire, fairy tale 18) Use of pauses, repetitions, false starts, asides (Sandelowski, 1991)
Identify narrative forms and functions in each central story (cont.)	<p>Each of these 18 narrative forms and functions were labeled and expanded upon for each story.</p>

Step	Process
Develop narratives for each participant	<p>The research question was asked of each 'central' story. Observation notes, reflexive notes, field notes, art and art narratives were pulled from at this point to support or refute the central stories. Interpretation of the participant's stories from the analysis of form and function led to writing a data analysis story summary for each, the narrative.</p> <p>A flow chart was developed from this process for each participant that detailed all told and central stories.</p>
Cross participant comparisons and development of a meta narrative	<p>Each of the story summaries were grouped with like stories, color coded, and labeled. These groups were formatted into large diagrams. The diagrams were merged into a larger diagram.</p> <p>Agreement/disagreement to relevant literature was noted. Upon completion of a large diagram, including all data, the meta-story was developed during two analysis sessions with thesis committee members and peer reviewer. The meta-narrative included three parts: the main story line, subplot one, subplot two, and a contextual story.</p>

Appendix H

Narratives (central story summaries) for each participant

Participant 1

Falling down story

This descriptive story is in three parts, part one illustrates how her hip replacements and avoiding damage limit her participation, the second is about her 'big fear' of falling in public, with a story of falling at the beach, and the third is a very short story of how her son observed her dislocate her hip. The main function of this story is relaying what falling down means: emotionally, physically, practically, and to her children. Emotionally, falling down in public represents "a big fear of mine". It is "hard to admit that you need help", and "upsetting" to her to see her son "standing over in a corner bawling his eyes out because he didn't know what to do" as he witnessed her dislocate her hip. When falling at the beach, she said her "only option" was "...to sit there and laugh, because it was one those scream or laugh or do something...". Her voice was quiet and subdued when she says "...you are at the mercy of people and people don't stop nowadays" and "If I fall, I can't get up". Physically, she "can't participate in all of they activities they want me to do, like tobogganing or skating...mostly because of the hips, I've had them replaced and if I do fall down I can damage them...which I don't relish the ideo of doing...it really does limit...my kids have basically lost out of that whole activity". Practically, she states, "OK, how do I get up?...if I fall I can't get up". Her son witnessing her hip dislocation while her husband was searching for the ambulance necessitated "...sort of gathering myself to be able to talk to him to get him calmed down to explain to him...that upsets me, because no kid should have to deal with that and be that concerned about their mom".

This statement is closely aligned with her attitude regarding their understanding of her arthritis in different excerpts; she feels they find it "confusing" that grandma

can snowboard and mom can't" but states "it's been who I am for them; it's not been that they have had to learn". Paradoxically, she "basically...train[s] my kids" regarding how they deal with the influences of arthritis in their daily lives, such as wanting to be lifted, or lifting a milk jug. Although she sees herself as a teacher, "we have a little talk and I showed him my x-rays"; her "priority is them" and making sure they "experience life", as a whole, not only experience her arthritis. Parallels can be drawn with her use of "THE" arthritis, (versus "my") with emphasis on her disease as resting somewhat outside her body, to her, having arthritis is "just part of my normal day" and "the arthritis does not consciously play into my life".

Tensions that stand out between what the uncertainty of falling represents and what she can/has to do to manage falling. Falling represents uncertainty, because "really on a public sidewalk, there's nothing, and you are kind of at the mercy of the people and people don't stop nowadays", not only that, the public represent people who may only "...supposedly" help you, versus really help you. On her part, she adds a comedic element to her story of falling at the beach, laughing, because "what else could I do" and laughing was "...the only option": "her dog was running circles around us, and if you had a video it would have made it to funniest video because what else could I do?". This is contrasted with "I quickly had to gather myself" and "how are we going to work this and get me mobile" when she has fallen: a sort of self sufficiency based on her limited resources at the time of a fall. The story was told with a tone of fearfulness, but again the tension is uncovered in her character portrayal: a problem solver, but also fearful of being a victim. Striking parts of the story include relaying her kids "...have basically totally lost out" on skating, as her husband does not skate, but interestingly she sees her self as "...the skater in the family". This reflects many instances in the larger interview where she finds it "tough" to give up the physical activities, especially when she just wants to "get out there" when there is not someone to assist her children to do things, and the "consequences" include her eldest son not being able to ride a bike. The statement that she is at "the mercy of others" is also striking in that it relays a fragility and fear that is contrasted with

stronger parts of the interview, for example, when she is speaking about the benefits of being at home with her children even with dealing with a chronic illness, and her authority on being the teacher of a “learning game” that is living each day with children, and with arthritis. The universal story structure is tragedy and comedy; she mixes both and provides comedic release in parts. The seriousness of being upset when her son witnesses her fall is contrasted with the innocence of her eight year old son’s “picking up” on her pain, “Are you OK mom? And yeah, Mom just did this, the night that I dislocated my hip...”. Paralinguistic devices she utilizes include “...um” and pauses to transition to the next stanza. The story is told in the past tense, with some reflections in the present tense. “Lost out”, “big fear”, “It’s hard to ask for help” “the hips” “at the mercy of people” are small impactful phrases she uses throughout.

“I think just like plain old motherhood, it’s a learning game as you go along”

This descriptive story a “multi vignette” story that is mirrored in interview 2. The first part of story relates her frustrations. The second part relates disciplining. The third part relates things she “has” to do, and reflects the “incorporation” of strategies into her life. The main function of this story is relaying what the ‘learning game’ represents. She “learn[s] as I go, I just live it and work around it”. Key events in her story of frustration is represented in a highly significant phrase, “If it’s on the floor, I can’t do it”. This is in tension with the phrase, “I tend---try to not particularly go up and down the stairs too much” and “I could go and get it [milk downstairs] it’s just---um---kind of gives him a bit job to feel that he’s helping out the family...”. The tentative vocabulary here is also in contrast with times she is decisive about what she need to do to avoid ‘throwing everyone’s life off kilter’: “I know with the kids I have to be sort of more---more willing to take, say, a Tylenol...” Some activities she has some choice in whether she can participate, in others, she does not; indicated by the word choices she uses: strong versus tentative. In this instance, she gives an example of learning: “So---they have to climb up, sort of to my height, so they’re my height, so we are at tables”. This is

the structure of this story: she gives an example of what she cannot do, then an example of the 'learning game' thereafter. If her daughter gets hurt, "she is so heavy now that I actually have to get her to climb up on her chair and I can give her cuddles...".

In the discipline section of this story, if she cannot "run after then" when they are out, "...I can't do that, so I basically have to train my kids". So "just learning" includes both training her kids, and doing things specifically: expressing anger, and verbalizing, using 'reverse psychology', training her kids (climbing up, sitting at tables) and "I have been known to grab them by the ear...or I'll tell them if I get up, and then go and get the rubber spoon". Again, the same pattern of word choice and following an example with a 'just learning different coping mechanisms', or evaluation and resolution.

The third part of the story has a distinct tone. She uses the words "I just---: "I just live it and work around it"; "...It's just part of my normal day". "It's just—I've sort of worked my life that it's on this floor"; "...it's just---I'll take the laundry down I guess because I'll just kick it down, it's not going to get much dirtier"; "It's just something that we've always done since we've been together" "It's just, we'll do it when he's [husband] home". Contrasted to this is the word 'could'.

The key actors in this story are the participant, her husband and her children. This story revealed that she places high value on "learning different coping mechanisms" and has a definitive tone: if this happens, this is how I deal with it: with "just learning as you would with anything else, just like plain old motherhood, it's a learning game as you---as you go along. And you just have to learn the things that work for you and be open to trying a whole bunch of different things". The universal story structure is a moralistic tale. She portrays herself as someone who has a set of 'learning' options in store for herself or her children, no matter what occurs. It would seem that "I just do ____" is paramount. The learning game is "...not really a conscious thing/I don't really think...": this phrase is featured five times in the story. The purpose of this phrase and numerous examples is in response to the question: "OK. I bet you probably...just do things you don't think about because it is so incorporated into what you do". I wanted

her to reflect on the products of the 'learning strategies' she had mentioned and trace back to an event, or an instance. While there are things she stated she would not do by herself, like take the children on the ferry by herself or go swimming, "I can't say that that's because I have RA or because taking three kids to the pool or on a ferry is just to me is not very much fun". This is exception to the learning game as it does not enter into the realm of possibility, hence the word choice "I won't do it by myself".

Participant 2

"Cooking: the same for everybody but slightly more overwhelming for me"

The main function of this story of 'overwhelm' is to relate how fatigue affects meal planning and preparation for this participant's family. A tragic unresolved story, it leaves us with our own and the participant's unanswered questions. Thus, her character portrayal is one of questioning, overwhelm and attempting to be successful in this activity.

The key events in this story are related; all vignettes tell of disruption of her role through the effects of fatigue. The story is told through contrasting meal preparation and shopping on different occasions, through the repetitive structure of past and present. Vignettes in the past are followed by the paraphrase 'and now' or 'but now' to signify a shift to the present.

Vignettes set in the past feature words like "crying", "overwhelmed": "I remember grocery shopping...trying to decide what to have for dinner, and you know I would think I was going to do something and I would show up and they wouldn't have pork chops or something—and I can remember just crying and having to leave the grocery store because I couldn't come up with another plan---just being so overwhelmed...". The second vignette is related her thoughts on "brain function and the fatigue": "I was very concerned about it at one point where I wanted to have a---I actually had a---MRI...and an assessment because I just---it was when I was still quite ill, but I was going to be cooking a turkey at

thanksgiving and I could not for the life of me even with a paper and pencil how long I was supposed to cook this turkey for, and you know, it was 16 pounds times 20 minutes, and I just remember being---and I was stressed too, because there were people coming for dinner...that was the moment when I knew something was going on mentally...whether it was just due to fatigue, which at that point it probably was, because...I was on some of those biologic medications, I was thinking, OH NO, they are causing brain damage...".

Vignettes set in the present address the tensions set up in the stories of 'overwhelm' but do not resolve them. She uses strong words: "And now...I hate cooking. I used to love cooking...Dinner is now a chore, which is sad." She delicately attributes this partly to her family's food preferences and ages of her children, and partly due to arthritis. She comes to the conclusion that "...you know sometimes you have to---be able to decide what really has something to do with you know, you know is your disability, and what is sort of the same for everyone but maybe slightly more stronger for you". "The same for everyone" refers to other mothers with children she knows who are also trying to prepare meals, make school lunches or do laundry. She describes some strategies she uses, such as a suggested "...weekly meal plan...like Monday was the pork chop night and Tuesday was...and that really helped me get going" as well as "I just try to do things simply and you don't want to mess up too many things that you want to clean...and try to make stuff that people like..." She remains unsure if it the difficulties lie the amount of time allotted for planning or "...energy to think" about what they are having for dinner. She describes herself in the present as a "procrastinator": "I wish I was better at this but it's so much easier when I have decided, you know, by morning time what...we're gonna have...if I save it for 4 or 5 o'clock...I'm a procrastinator now, which I didn't use to be either, I put things off..." .

One key phrase "I just hate being tired all the time" is again brought up again at the end of this story, when reflecting on preparing the turkey: "I think it probably was just fatigue and pain, and that's---I still have those questions, is it

just the fatigue?” This question lingers in the air. As with her first story, fatigue and energy are key ‘characters’ and support unresolved tensions.

“Not everyone has to be the soccer star family”

This moralistic tale seems to be told from a reflective standpoint; the teller shares her thoughts through stories of participation with her children in activity. The main message is: “I just do what I can when I can do it, and that’s it”. The story revealed that her participation is influenced by family likes, dislikes, physical abilities of herself, her husband, and her son, and ultimately has resulted in a well established and thoughtful view: “You just have to try and make the most of it”. Key actors include herself, her husband, and their two adolescent children. Initially, it would seem this is a story of comparison, of comparing her own family with others, but it is not. This story reveals that participation is affected by many factors, including energy and fatigue balance, but in the end, her efforts are “good” and she is comfortable with her level of participation. She tries to describe this process of coming to terms with it through highly structured vignettes.

Her story telling is structured in a particular way. She tells of a challenge, then a reconciliation and evaluation. Her own standpoint is told via an example of participation in activity with her children. The first example describes how “My kids are so different, one of them [is] social and one of them is not...I try and keep them organized”. The challenge: “...there are some families where the kids are involved in five different things, (reconciliation) and we’re not like that at all. I don’t think I could survive that (evaluation) but they don’t like to be like that either, so it’s a good thing”. The second example she gives is about her son with special needs. She describes the process of trying to get him to go to soccer, but “...his heart just wasn’t in it” and the difficulty: “It was just ...so difficult,...I don’t want to fight with him about getting up one more morning a week and getting ready, you know, it was too much energy for me”. The challenge is followed with reconciliation, which is the encouragement for him to choose something physical, “outside stuff” and do it independently. The evaluation: “He would rather be at

home on his computer or playing Lego". The third example describes how she and her husband are limited by knee injuries and arthritis respectively: "...neither one of us can do a lot of those physical things [ride a bike, kick a soccer ball]" followed by the reconciliation: "---but not everyone has to be the soccer star family or the---you know". The evaluation follows: "You just have to try and make the most of it..."

Fatigue and energy factor highly in this story, mentioned three times. Following the example with her son, she states: "...but there are certainly times when---like I would just love to have a week where I didn't feel tires, you know, an just have ener---Like I don't ever feel like I've got energy, you know, even when I wake up. Like it's never, "Lets GO!". I sort of make myself do those things---". The second example follows: "Having enough energy to think that I want to do things, but then, you now, if I had the energy to run around and play tennis or soccer—then I would have to stop. Because it would be too painful to do it".

Following these vignettes, the tension created is dissipated by reflection, often joined by a positive comment with the word 'good': "I guess I just---I don't think too much about it, I just do what I can do..." Making herself 'do things' is "probably a good thing, 'cause if I didn't have the kids I'd probably be spending way more time in bed and not doing those things and they're probably good for me, but I just---I have to psych myself up to do them. And you know, it's good, because you get out there and it's fun and stuff like that so I'm glad that I do do them..." In the last part of the story, she says, "...I think I have a very positive attitude---your life could be a lot worse...just be thankful for what you do have...there is no point worrying, it's like worrying about whether you're going to get hit by a car...you just can't worry about what could happen". This last statement is a grand 'reconciliation' and reflection.

Participant 3

“We’ll just lie down together”: Learning about her son’s needs, balancing her energy

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The key events in this story are related; all vignettes tell of disruption of her role through the effects of fatigue. The story is told through contrasting meal preparation and shopping on different occasions, through the repetitive structure of past and present. Vignettes in the past are followed by the paraphrase ‘and now’ or ‘but now’ to signify a shift to the present.

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Vignettes set in the present address the tensions set up in the stories of 'overwhelm' but do not resolve them. She uses strong words: "And now...I hate cooking. I used to love cooking...Dinner is now a chore, which is sad." She delicately attributes this partly to her family's food preferences and ages of her children, and partly due to arthritis. She comes to the conclusion that "...you know sometimes you have to---be able to decide what really has something to do with you know, you know is your disability, and what is sort of the same for everyone but maybe slightly more stronger for you". "The same for everyone" refers to other mothers with children she knows who are also trying to prepare meals, make school lunches or do laundry. She describes some strategies she uses, such as a suggested "...weekly meal plan...like Monday was the pork chop night and Tuesday was...and that really helped me get going" as well as "I just try to do things simply and you don't want to mess up too many things that you want to clean...and try to make stuff that people like..." She remains unsure if it the difficulties lie the amount of time allotted for planning or "...energy to think" about what they are having for dinner. She describes herself in the present as a "procrastinator": "I wish I was better at this but it's so much easier when I have decided, you know, by morning time what...we're gonna have...if I save it for 4 or 5 o'clock...I'm a procrastinator now, which I didn't use to be either, I put things off..." .

One key phrase "I just hate being tired all the time" is again brought up again at the end of this story, when reflecting on preparing the turkey: "I think it probably was just fatigue and pain, and that's---I still have those questions, is it just the fatigue?" This question lingers in the air. As with her first story, fatigue and energy are key 'characters' and support unresolved tensions.

"It's so different for me"

This is a moralistic tale, where the participant portrays herself as a crusader. This excerpt is interview #2, and while there are parts that are not

storied, she uses seven different vignettes to describe how she is 'different' than other mothers may be.

First, she describes what a mother is ("caring selflessly", "multi-tasker", "multi-rolled"), and if she sees herself in when she thinks of this image of a mom: "Maybe but---like, I don't know. Some moms...do everything for their kids...teaching...very hands on". When she had her son, her "idea has changed", and contrasts herself to the mother image: "...you know, its more like being a mom but teaching your kids how to do for themselves, not so much by doing". She sees herself a "caregiver", then "teacher or facilitator", followed by being a "playmate". This aligns with the first story of 'change' and learning.

The next part is describing how things are different for her: "I just find its interesting going to ladies bible study at church, and the majority of the women are moms, and discussing issues and how its so different for me". She tells a story about "little things" people say: she does not bring the shopping cart back to the store when she is finished: "...and no, I'm not bringing it back, it's too far to bring it back, I'm too sore to bring it back". The next vignette she introduces by saying "...it's just interesting how everything is differently affected..." Women at her church didn't feel the pressure to serve in children's ministry in church, and she says, "Well, I do, you know my name is put on the list, before I even talked to the person in charge, and I said, 'you know, it was a bad time of year for me, you know, like I had just had surgery and [husband] has softball'---and it's just interesting how it's a different view and different issues affect you as a parent". The transition next is striking; "Just all around, people don't think about those things, they look at you and they thing everything is normal and fine. I don't know if it is eye opening for them, I hope it is, because people have this narrow view". She gives a story about her friend, who has vision loss, and herself with their children 'bumping in to people' and the resultant 'scowls'; "...they think you're being rude, and think I'm the one with the problem, why don't I---and it's just so funny, the stereotypes...people need to be more educated".

The next story is about "how much more energy" it takes to do certain things, like fastening car seats. She says, "It might be safer and all of that but it's

not easier to use, even for normal parents, I think you find that". She expands on the lack of funding for help: "Like, I so need my cupboards cleaned thoroughly, but there's not funding. There are no sorts of support programs for people with disabilities in the young parent age". As her income bracket is just above what is deemed low enough to have practical help, "...what the medical doesn't cover for your orthotics or your wheelchair" and tells a story about putting in a wheelchair lift in her home and having to pay the costs, because "...we were too high of a [income] bracket". She counts herself "fortunate" that she has her mom for help, but says "...most people don't have that".

In this multi- storied excerpt, her circumstance is revealed as 'I'm different, and different issues affect me as a parent'. She contrasts herself against a 'normal' mother. Key actors include herself, her son, and others at church and in the community. There is a tension between what is available and not available to her in practical and financial help, and the image she has of a 'normal' mom and herself. Striking vocabulary includes "...others have a different view, different issues affect you as a parent"; and "They look at you and think everything is normal and fine". When asked to think of the image of a mom, and to think about herself, she says "Maybe, but---like, I don't know" if she is the same. She uses the word "different" many times; and sees the differences as 'interesting'. The main message here is that she is different, she has different challenges, and people do not always see how or why she is different. This difference is shown in the daily tasks and community, as well as the perceptions of others, from other mothers in her peer group to the larger structures of funding (medial, Canadian Housing Corp.). I chose the word 'crusader' as she is not only battling to have the services she requires, but also is vocal about others who do not acknowledge the differences. This impacts her life in the community, in being able to secure services, and in her ability to manage her home.

Participant 4

"I always wanted to be a mom"

The purpose of this story is describing why "I always wanted to be a mom". In small excerpts, she describes the importance of loving her children ("you can't live without it, really") and providing the environment they need. Having the skills to parent, being wrong, and teaching lessons about the important things in life are all featured in this story. The story is set in the past tense and present tense, and shows the pattern in other stories of her perception that thinking too much about the future is not helpful. Her use of false starts is telling of this. For example, "I always thought I'd like to have three kids, but after---". She tends to end thoughts in this manner, especially when it pertains to thinking of her life in the future, or appears to be a difficult place to "go" emotionally. In the story of 'others with arthritis', she says, "I can't worry about it because anything can happen to me---if you delve into it too much and read too many---you know, I would go onto the internet and read stories about other people with arthritis...but if you do that too much it can be just too discouraging; there is not much point in dwelling too much on what might happen, um---so I think I just decided to---(end). The tensions appear in this story are tied to her definitive language choice compared to the uncertainty that may be present in the future. Examples of definitive language include "I always wanted to be a mom...", "I always knew", "I always thought I'd like to have three kids..." "I can't imagine a life without kids" and "You know?" and "right?" (pertaining to the lessons she teaches her children by example) and "After I was diagnosed with the arthritis, it was like, no [more children]" and what she does not elaborate on, for example, "I thought I was a terrible mom because I couldn't take care of the kids, and that was the big thing, just feeling like I couldn't cope with looking after them. So that was very hard, but once I got through it and was feeling better, I mean basically because I can do pretty well everything". Note what is not present in terms of her conversation: "so that was hard" is not fully elaborated on, the whole emotional and physical

descriptions you may expect to be present do not feature in her story, what happened between this period of her life being hard and getting through it? Near the middle of the story, she “can’t imagine how lonely you would be if you”--- and again, does not finish her thought about the possibility of not having children in the future. In terms of “showing them examples”, this section of the story interesting in that the detail presented here does not feature in other areas. Three lessons in life include appreciation (“...trying to show them to appreciate...that you have to work to earn things...”) people way things they shouldn’t, and this is how you handle it; and how to deal with a teacher you don’t like. The phrase “you know” is featured strongly in this section, as if to say, teaching them is what I know how to do. Interestingly, she uses the third person in these lessons of life to her children, “you”, “they”, “we” “all make mistakes”. The stories are concrete, but rendered into 3rd person abstractions when she moves towards application in the future. Compare this to her statement “And of course I am hoping that they grow up to be good people...”; one of the few ponderings set in the future she allows herself to make. Emphasis is placed on the importance of having children by providing an example of a friend and loosely comparing herself to this) who could not have children, and said, “If I couldn’t have kids I would kill myself”. This strong language. She means to tell the audience how important her parenting role is. She is able to teach, love, provide an example, provide a “warm and loving environment”; it is interesting that her participation in her children’s lives is not demonstrated not by what she does physically.

Key actors include her children, herself, and to a smaller degree, her husband. The story was told with definitive, sure language in comparison to other stories. Past and future language does not figure prominently into this story. The effects of arthritis discussed figure prominently into the decision not to have children, but minimally into the examples of teaching her son and daughter she provides. False starts are figure prominently into this excerpt. Striking vocabularies include “I always knew” and “I always wanted”, as well as “you know”. Universal story structure is the moral tale. She portrays herself as

someone who knows this story well, and is able to give strong examples of teaching her children the lessons in life she feels are important. A substantive theme in this participant's stories is living day by day in her role, although things may be difficult, she minimizes the discouragement and avoids worrying. An undercurrent here is fear of thinking about the future, which finally features in the second interview.

"It hasn't gotten in the way, I still try and do the things "

The main function of this story is describing how arthritis impacts her activity, or things, with her family. Yes: But---. is the linguistic pattern she sets up throughout. This is striking; every vignette is framed with this device. Yes represents things she "Little things I can't do", or things she does that she can "still do". She then uses the word 'but' and thereafter describes consequences and adaptations. After this pattern, she lets us know that although there are limits in what she can and cannot do; a phrase or sentence similar to "I generally do almost everything. It's good" or "It hasn't been really---it hasn't gotten in the way..." is used. This last sentence represents what she really wants the audience to know, as it is repeated in various forms after every example, fifteen times in this story.

"It" refers to the arthritis, which is interesting us of language, as with another participant, the word arthritis does not show prominently in this story of participation. Following "it" [arthritis] she uses many different forms of telling it hasn't affected her life: "I generally do most everything"; "It's good", "it hasn't really interrupted", "It hasn't really been---"; "It's been really good" "...it's pretty---it's pretty---as far as that goes it is very manageable" "it's not too discouraging, really, because I know it can be sore for a while, then it can get better".

Key actors include herself, her husband and her children. In this 'sandwich' format, she is convincing, justifying, and explaining; this story tells us that she is aware of the things that are straightforward, but as in other parts, there are false starts in places there is uncertainty about the future: "I don't know

if it will stay the same or if it will change, I don't know, but----". This linguistic choice develops the participant's uncertainty in seeing herself in the future with regards to the effects of arthritis. The tension is set up with this rhetorical device. Most of the story is recent past and present. Her husband figures strongly in this section, as the "balancer", he will do the activity that she is not able to do, such as "the morning stuff with the kids" making lunches, and "putting the kids to bed". Allowing her husband to take over these activities, perhaps relinquishing her role, "Doesn't bother me..."

She compares herself to someone without arthritis; "we just need to know that I can't always do everything they might want me to, you don't have to have arthritis" and "...even if I am feeling great I may not want to do it or whatever they can, you know—." "...when you are a parent you are tired most of the time anyway, right?" This is striking in that she is telling us that other parents may not be able to do everything either, and their children accommodate.

This participant's portrayal is certainly one of not allowing the difficulties that arthritis may bring to participation in daily activities impact her emotionally, or her perception of involvement. The linguistic choice develops the theme of pushing off discouragement, staying in the moment, and making normal, even "good" her level of participation, which when taken at face value, the physical, not the nurturant, seems marked. The story was told to convince the listener. The story structure is strongly set up as a success story.

Participant 5

"I'm not always able to do the things other moms are doing, but I make up for it in other ways"

The main function of the story is to describe her "job as a mom" which is to "make up for [what she is not always able to do] it in other ways" because "that is what you're supposed to do". This story identifies her core belief, "I don't think you should have to (give up your stuff). "There should be—I mean in this day and age, there should be options for people not to have to give up their lives just

because of a disease". This is striking as well as profound; and figures prominently into her decision making in all time spent with her, and is a substantive theme. The "making up" is tied and key to the word "options": having and acting on options allows her to exert control, make things as they should be, and allows her to feel a sense of accomplishment being and doing motherhood.

She shares two important things about being a mom, the first is "being able to take the time to do the things that I want to do with my kids". The second is "...it's important for me to be able to provide". Provision is her "stuff". In other excerpts, this includes making food for them, exerting control in making healthy choices how and what they eat, being there for them, making cookies with her daughter, and cleaning for her family; these are things she "loves". Vocabulary she uses that is striking is "supposed to" (make up for not being able to do all the things other moms are doing) "should" and "shouldn't", referring to her daughter's life (should be like & she shouldn't have to have the disease). The use of this vocabulary demonstrates she has a strong belief core what her family's life has the potential to be, an ideal that drives her "doings".

There is a tension that comes from "not wanting to give up your stuff" (at this point referring in part to cleaning, which she 'loves') and how she makes up for not being able to do everything she wants for her family. The character portrayal here indirectly is a heroine and asks the audience to root for her; with a wish to succeed. Another character portrayal is "not any different than any other mom". In this story, what is important is reflected as well as how she, and her husband, make their lives happen. As in other excerpts, this is a story of control; her portrayal is one of a character perceiving life as if there are choices. She gives many examples of how she exercises her "options"; from calling her housekeeper "...if I feel like I need to", doing things if she is able, and if not, adapting by collaborating with her husband: "I mean, I'm able to do a lot of things as a mom, but because I have arthritis, as a couple, we kinda collaborate and---do it together", In terms of parenting, she "adapt[s]" by involving other people in her life, especially when she was single, and focuses on her daughter's needs: "...Do whatever I can to make [daughters] life easier", "I do

what she asks, when she wants” or uses finances to provide specific activities in the community for her daughter: “...because my I’m not able to do a lot of physical stuff with her, we put her in sports activities...we use our finances to our benefit in that way”. The key characters are her older daughter, her husband and herself. As a story of choice, because of the participation she is not able to do, she “makes up” for the areas she cannot participate in and generates choices. There is also a strong element of control; in other interview parts, if she cannot generate choice, she uses words like “depressing” and “anxious” “lump on a log”.

Key words: In this story, there is a belief in what she can do, typified by the word use of “do”: “do it together”(with husband), “I do whatever I can”. “I do what she asks”, “...we try to do pretty much everything that would make her life fulfilling.”(for daughter) “...take the time to do the things that I want to do with my kids”. “You just do what you can do---get around it”(for children). “That’s what you are supposed to do.” This story reveals a belief in the “I do”. It doesn’t necessarily mean she cleans, does sports activities, etc., but creates choice, exerts control, and exercises options. Thus the “doing” is not as much related to activity as it is the ability to be active in orchestrating decisions to allow her daughter, who figures strongly in this story, to “do” (drama, sports activities). This orchestration of decisions reflects back to the core idea that people should have options despite having arthritis.

One more striking word is “crippled”: “She’s (daughter) gonna know what it’s like to live with a person who doesn’t—you know, isn’t able to function at their 100% all the time. So that’s nice, I mean, I’m not crippled or anything, but---.” This description is similar to P4: “I certainly don’t feel like an invalid or anything---”. Both ended their stories with these phrases. The function of this may be to alleviate some of the discomfort, perhaps, of seeing the character as less than capable. Also similar to P4 is the portrayal of her husband as her “...evening outpoint”; P4 used the word “balance”.

Emotive or feeling statements do not figure strongly in this excerpt. Additionally, this story is more abstract, deals with her ideas of being a mom versus specific stories of events. It sums her thoughts of what it means being a

mother, as no different than any other: "Yah, I mean every mom goes through struggles and it's hard being a parent, but you just have to, I mean, if you're gonna become a parent, you have to expect that. So you just do what you can do—get around it...I'm not always able to do all the things other moms are doing, but I make up for it in other ways. That's your job as a mom. That's what you're supposed to do". This story is framed as moralistic tale.

"We have done a lot to adapt to make it better, and that's good"

P5 is a 35 year old nurse on maternity leave living with her infant daughter, husband and 10 year old daughter in a small town in the Okanagan. When asked why she wanted to be a mom, she said "... I've always wanted--- to be a mom" and "I've always loved their energy and resilience". Her interview is somewhat divided into two areas: returning to work as a nurse, and caring for her family.

With her older daughter, "I love---- making them dinners and--- birthday parties and I love umm, just hanging out and spending time with M. I like teaching her about being a girl and---and how to be a good friend...so I do whatever I can to make her life easier and to make her life what it should be. And that's important 'cause I have this disease, but M. doesn't. She shouldn't have to". She describes her daughters' perspective: "[if] I'm feeling good, then I can go for a walk and make supper and, but some days I can't do that and I have to select what I'm gonna do. And she doesn't always like that, but she lives with it and she doesn't complain-- and she's good-- that way." Her infant daughter was 8 months at the time, and she described doing things differently (such as asking for help to carry the car seat) and challenges: "... getting her dressed sometimes is hard. But you know, I don't have to rush and I persevere and [husband] helps a lot". Her husband's presence during the day is a huge support: "I mean, he could work outside of the home, but, and a few times he said 'maybe I should get an office away from the house', but I don't know how we would function. I just don't know. It would be difficult. Cause I get-- when I get down or depressed, its nice having company...and as a couple, I mean, I'm able to do a lot of things as a

mom, but because I have arthritis, as a couple, we kinda collaborate and--- do it together, that's important". Two activities she described that were important were cooking and landscaping: "... I love cooking. I love making dinners for my family. It's one of the things I can still do, so I just spend lots of time doing that" but landscaping was one thing that she had to relinquish: "I had started a landscaping project and had someone come in and finish it and I just didn't plant any flowers this year and then I did that little display for Thanksgiving because I was just so depressed I didn't have anything". This perspective returned when she was describing other activities: "...difficult. And sewing. I used to sew all my own curtains and stuff. I did a few little things, but I can't do what I used to do. And painting, decorating, I used to love to do that kinda stuff. Now I have to get someone in to do it. That's kinda depressing [softly]. I just feel like I just don't do anything with my life, it's not very productive right now, even though I'm at home and being a mom, it just, I don't know, I guess I'm used to just being more---more of a service to society than this. So that's kind of hard". This comment is closely tied to the importance of her work of being a nurse. Her biggest barrier was described as lack of energy; she described being able to feel it "drain from my body" and attributed it to lack of patience with her family, especially her older daughter.

With every difficult aspect of arthritis, she often paired it with a positive viewpoint, of hope and perseverance: "My physical energy, cause I have a lot of-- knowledge and I have a lot more, not physical energy, but spiritual energy, lots of energy that can go to work. It would be useful in a lot of areas, but my physical energy is just not-- there. Some days it's worse, I mean right now my arthritis pretty bad cause I'm not taking any medication, so, but umm, if I can, if I have the energy, I can live through the pain. I'm pretty--- I'm getting better at knowing what my limits are. So that's good. But that's part of the pride issue. Not wanting to give up your stuff, right?" She describes a supportive nurse manager who is looking for a position she can do, and is hopeful something will come up: "Yah, I was kinda worried about going back to work, but you know if you put yourself out there and put your concerns out there, people are willing to help you, that's---

that's nice." Her anticipated return to work is described in terms of adaptation: "It will be interesting to see how her, how P., M. and B. will adapt when I go back to work; [husband] might choose to get someone to come in sometimes. We'll see. But I don't think it will be much different, as long as I'm having--- if I only stay positive, I think that's the key"

Her story summary can be captured by these statements: "It's nice to know that there's options in every aspect of my life." "Yah, I mean every mom goes through struggles and it's hard being a parent, but you just have to, I mean, if you're gonna become a parent, you have to expect that. So you just do what you can to--- get around it...But, you know it's not, it's a little different, but we've done a lot—a lot to adapt to make it better. So that's good."

Participant 6

"And so I'm part of it, but just not in the same way"

This is a second success story, whose main function is to describe how 'I'm part of it' with regards to activities with her younger and older daughter (3,10). The key actors include the participant, who portrays herself as an "evaluator", and her nuclear family: her children and her husband. She uses many small vignettes to tell the larger story.

This participant utilizes a specific structure in her story. She tells an activity based participation challenge (biking, golfing, hiking, and skating), prefaced or followed by the phrase "you know". This is followed by "and so..." which signifies the resolution of the challenge. Key activities are participation in her younger daughters mother goose story time, golfing on her own when pregnant (both told in the past), hiking with her older daughter, biking with her family, and skating with her younger daughter (present).

Her circumstance is told through evaluation of the activities before she begins them: "...I think it's a point now where it's very balanced...some activities you just, you either know you can't do it [golfing, hiking] or you think it would just be easier if I didn't push myself to do it [sitting on the floor with younger daughter]

or try to do it and then fail [biking]. So I just do other things instead that I know I can do". The things that she chooses not to do or cannot do she "misses": "The whole family has bikes and S. started riding her bike independently now and I would like to get out and do more things like that".

Striking vocabulary, or "emotional challenges", includes "It's hard", "I can't", "That's a challenge", "I try to ignore it". This sets up tension in the story. The tension is resolved vignette by vignette as she describes six ways of how she deals with participation challenges. One way is "...I volunteer for other things...so that makes up for it". The second way is adaptation: "And even if you ask me right now, 'what would you do differently....because of your arthritis' I don't honestly know how I would say! I know there are things that I do differently than I used to do. I just, it becomes so much a part of my life, I don't see it as different anymore". The third way is practical help and knowledge of what she requires on a daily basis and understanding from her children, who she describes as 'independent' because of her arthritis: "You know, like the kids, the kids know the little rubber things that you use to open jars, they are my hands ---'oh, mom do you need your hands to open that jar?' So that's just second nature now". Her younger daughter will do up her own car seat, and her older daughter is described as very helpful: "...a little pack horse" as she will lift and carry groceries and her younger sibling. The fourth way is "I just do other things instead that I know I can do". This includes volunteering as a Girl Guide leader; which does not present the "physical challenges". The fifth way is her husband's willingness and ability to be involved in the physical activities, such as skating: "...he came on his lunch hour. I met him at the arena...they both put their skates on and he took her out skating". Lastly, she is '...part of it, but just not in the same way': [child]: "I skated all around the arena with my mommy and she's walking". [P]: "Yeah, so I wear the special treads on my shoes and walk beside her. And so I'm part of it, but just not in the same way". This last sentence represents her mindset and identity as a participating mother.

“...We’re just gonna have a day”

This is a moralistic tale, whose main function is to describe how this participant is involved with her two children: “I want them to be as active as possible or try to encourage that and support it”. The key actors include the participant, who portrays herself as “lucky” to be at home with her preschool daughter and available for her school aged daughter. She uses one main story of deciding to throw “...everything aside and say, nope, today it’s just play time with her and I---” to let the listener know of the importance of spending time with her children.

The listener is orientated to her story by way of past circumstance. She went back to work when her older child was 8 months old: “So---I had a great babysitter and everything...but you do miss out on a lot when you’re not home with them...”. Presently, she says “...I feel so, so lucky to be able to be home with her [preschooler]. Unfortunately part of it is because of the disease”. Turning again to the past, she tells us it was difficult to play with her younger daughter: “...babies like to lay on the floor and play with their toys and crawl around and I couldn’t get down with her a lot, so I felt like I missed out in that part with her---”. As she felt like she missed out on some of the time with her daughters as infants, “I think sometimes I tend to make up for that now”.

Striking vocabulary in this story includes the key word devote, used three times. “...I try and do it all, which sometimes isn’t---doesn’t work out but, I don’t know, I just try and devote as much time to them as I can”. With her younger daughter, “I just devote the whole day...to her”. She says, “I’ll say, forget it, I’m not answering the phone, I’m not doing dishes....we’re just gonna have a day and we’ll go to the park and we’ll stay here or go out and ride bikes---she’ll ride her bike and I’ll walk with her or she’ll jump on the trampoline”. With her older daughter, she “does a lot...she’s in a lot of activities with school and girl guides and horseback riding...I try to do it all...”

Interestingly, she tells of her husband arriving home at night and saying “Did you do anything today?” Her response is “Oh I had such a busy day and it

was so---but it was a total day to devote to her”. The omission here, or ‘false start’ is interesting, we are left wondering what she may have said about her day, it was so---what?

Her circumstance revealed through this story is of a mother who is taking advantage of the time she has in ways she is able to with regards to participating in her children’s lives. The story is told with past orientation followed by present ways of participation, using the narrative form of verb tense to situate the present, which she frames as “making up” for time she was unable to spend with them due to working or the limitations of arthritis. The key turning point in this story is in the phrase is “...but I’ve just really, you know, some days...” as she transitions from the past ‘missing out’ to the present ‘making up’. This turning point also functions as a contrast between past and present.

As a listener, you find yourself finding this story tender and poignant. As with other stories, she utilizes the phrase ‘you know’; in this story, to signify her evaluation, or the significance/meaning of the action from her standpoint for the listener.

Participant 7

Family Ties: “Watching her evolve has been amazing”

The main function of this story is the participant’s sharing her perspectives of seeing her daughter mature, and secondly, her parenting philosophy. As in the other story, there is arthritis does not figure into this story. She tells a few vignettes of ‘then’ and ‘now’ to give meaning to the word ‘evolve’. She sets up the story by answering an initial question:

I: So what part of motherhood is, tell me about what parts of motherhood that are really valuable to you personally.

P: Well, valuable. Just watching, I actually wrote this on the survey too, just watching my little girl evolve into a young lady has been, that’s been amazing. Just somebody who was so needy of me, to now you know, just be blossoming in all different areas, you know, academically, socially, umm, physically, you know, as an athlete, a dancer, so that’s been the most rewarding. Absolutely. It’s

unbelievable when I look at how tall she is now and (laughing) what she looks like. Yah, so she's a pretty good kid. So yah, motherhood. It is great. No regrets. You know, and sometimes, you don't know if you're doing the right thing, like that incident we spoke about. You want to do your best. You don't want to overreact. You don't want to under react, so I'm just, I try and do what my heart and my head are telling me, cause I do listen to my heart quite a bit. I think that's important."

The second story is relaying her daughter's wish to be a doctor. She tells a 'then/now' story of her daughter in kindergarten:

I: And what does your daughter aspire to be.

P: A doctor.

I: A doctor?

P: Since she was 5.

I: Really, wow.

P: Kindergarten, she wore a white... I can't remember what we put here in. It might have been like my dad's... a white dress shirt and Paul had this, umm, this label he had worn to some kind of seminar, you know with your name, like a nametag, so we just put another paper, we put N. written on it. I remember, oh, it was Dr. [last name] for kindergarten. It was quite funny. So now, umm, she's actually, you know there's the take your child to work day on the first. So, she's going to shadow [physician] who is an orthopedic surgeon. So, good for her if she can, you know. I want her to be whatever she wants to be. I just want her to be happy. That's my goal for N. I want N. to be happy. It's very good. I'm very pleased. I'm glad that N.'s happy about it.

This excerpt is linked to the picture she painted and the narrative about it. It is a red heart in a blue background. In this narrative, she repeats her wish, her main wish, for her daughter to be happy. She uses the story of her daughter using her backpack from many years ago and 'defending' it as it is bright orange, and remembering her daughter in the playground at 18 months: "Yah, it like yesterday, but it's gone by so quick. That's what I say to people, it's, just enjoy it. You know, I remember her at 18 months. We just had a ball. It was so much fun

and going to the park and in the buggy and I'd walk with her, like, go down the hill and to the beach and take her on the playground there. Now [husband] and I drive by. We take the dog down there and then we are looking, look the kids, the ship's still there, little ship and she used to climb up the ropes". What this story is trying to say is despite the changes, there is continuity in her role of mother, and it is grounded by her wish for her daughter to be happy in life, which is as present today as it was when she was little. Then/now vignettes are used to accomplish this.

She talks to me about everything

The main function of this story is describing through story an example of the kind of openness this participant has with her 14 year old daughter. This openness permits her to listen to her daughter, give information, which in turn allows her daughter to "...make good decisions".

This participant is setting up the story in a way that encourages us to listen carefully; it is if she is letting us in on a private side of her parenting life: "Yah, they do and she tells us, like she, one very good thing is N. talks about everything. I know the things that she tells me, I would never have dreamed of telling my parents or my mom. You know, but she does, she tells us and you know, we have an open discussion about it and it just happened not too long ago..."

The key event in this story is her daughter being 'buddied' with a new classmate transferred from England, whom she begins to spend time with. The key turning point, or complication, occurs when "N. came home and she's telling us these things, and I said well it's because, I mean we have spoken to her about sex, you know, drugs, alcohol, but this was really, I was quite overwhelmed with the sexual content". The evaluation, or significance, is stated: "We didn't forbid contact; she stopped on her own...so I was very happy about that". The key actors in this story are herself, her daughter, her husband, and the new friend. The story revealed that this participant values open communication with her daughter. Key words include "open communication" (used twice), "talked in

length”, and “N. talks about everything”. The story was told with a structured beginning, middle and end as a fairy tale. The last part was co-constructed with the interviewer:

P: Do we intervene right now and say ‘no, you can’t see her [the classmate of her daughter’s].

I: Or do you give her the information she needs—

P: Right.

I: To make the decision.

P: So that’s what we did, we didn’t forbid contact. I: Good parents, good parenting, great.

P: She stopped it on her own. She said ‘you know, I was nice to her, but I don’t want to hang around with her. Ok, phew. That’s what I thought.

I: That’s great.

What is interesting about this participant is that the effects of arthritis are not mentioned in either of her central stories. In the past, she mentions that things were difficult, and still has to manage some fatigue, but for the most part, the emphasis is on the later part of parenting: guiding, encouraging, and building relationship. The character portrayal develops the theme of the closeness of the relationship between herself and her daughter, which is seen throughout the interview.

Participant 8

“I don’t want sympathy, I just want a little understanding and patience”

The purpose of this story is describing accounts of understanding and sympathy that are positive and negative. She uses a number of small stories within the larger to get the point across that some people see the effects of arthritis, and understand, while others do not. She uses the word “like” when she is transitioning to a story, then separates these stories with an evaluation/reflection that is deeper in nature and reflects her understanding of how she is or is not understood. Most of her examples refer to participation, and

the examples are used in part to show when people see or do not see her arthritis; it affects the level of understanding /patience she receives. The visual 'seeing' of the arthritis is an undercurrent in all of the stories, with key phrases reflecting this: "I looked like a gimp when I was walking..." "...when people look at me, you know, they don't even think---", "So, people can look at me"; "I see my family...they didn't start showing any signs...", [my boss] will look at me..."

In the first story, she gives an example of other mothers who use aids to participate in self care and household work, and says, "Their lives are so different from mine...Like they, they're so---opposite of what--- when people look at me you know, they don't even think---" [I have arthritis]. The point here is with these women, you can see what they use in their daily lives to mediate the effects of arthritis and participate, and she does not have any of these aids, somewhat due to family resistance. Therefore, she is telling us, 'you can see they have arthritis, you can't see mine'.

The second story expands upon "they don't even think--": as in most kid's activities, she was asked to help, and although she said, "...well, nothing physical, but if you need anything done otherwise, I will do it", she was asked to be assistant coach. She says, "I can stand on the sidelines and cheer, I can do stuff, but don't expect me to kick the ball or run after it... They're like, 'well why?' Nobody else is gonna do it'. Well, you know, umm--- this is not something I want to Sunday and then not be able to go to work on Monday. So, people can look at me". This is an example of the soccer organizers not seeing her arthritis, and therefore, not understanding her limits, even though she asked not to do anything physical. If she is standing on the sidelines, "...people can look at me". I think she is trying to say, Well, I can do what I can do, and if I am on the sidelines, well, people can look at me. And that is OK.

The next part is a reflection: "It is, but it's not something I wanna---tell the world. Like 'oh, I have arthritis, so-- you know.' Cause then they also know---they think 'oh well, from what? You know, you must of lived hard or something'. If I didn't have it, I wouldn't understand."

The following story is about her family and herself. Her family "...didn't start showing any signs of it till they ere in their 30's or 40's"; whereas she remembers having her arm in a sling in elementary school. The tension here is between having arthritis in her childhood, but even now, the signs now are not visible, unlike her relatives. She expands to sharing the story about her uncle Jim, who has arthritis, and says "...he understands and he knows, like he just had knee surgery...he looks like a normal person when he walks..." Her uncle understands: "...he'll ask me questions and I can ask him questions and...just a little comfort I think---?"

Following is again reflection: "Not really comfort or necessarily support, but just that okay, you know what I'm going through. And I know where you have been. And I can totally respect that. Without the 'oh, poor baby', cause you see, I don't want that. I just want somebody to understand I will do it, it will take me a little bit longer, but I will do it".

The next story tells of being taken off medications, and the result was "I looked like a gimp when I was walking", and being "embarrassed". Again, she says that people would look and say, "Why are you even walking?"

Following this is another reflection: "Well, if I stop walking, you know, when you don't move, it hurts more. You have to keep your range of motion, which is the most important thing. I'd be like 'Jesus' [laughing], and I was embarrassed. But. But yah, I don't want sympathy I just want a little understanding and patience. Patience is good. Patience on my part, too".

The next story is about the understanding she gets from her boss in a small business. Because his wife's injury and subsequent pain gave him insight, he understands her need to go to a specialist early, and allows her to modify her work: "...so he'll look at me and he'll go, 'You're gonna go and sit back at your desk there and work today. You're not gonna be out here walking. You just look like you don't need that'--- so. He's very nice. And if I say 'oh, I have to go to my specialist, I have to leave in a half hour', he's like 'okay'. That's really good". The work is also good because it allows her the flexibility in hours to "Put your kids on the bus, come to work, and leave when you have to get your kids off the bus.

Where am I gonna get that. Nowhere that I know of..." The lack of understanding is also shown through her husband's comment of "Well, just quit" as sometimes, the workplace is not "a happy place to be" because of family dynamics of the owner and his son. In this story, she says "There's life outside my house" which includes socializing and staying challenged mentally.

This larger story is difficult to analyze. Using structural properties, it is possible to see what she was trying to convey. She uses separate stories separated by an evaluation or reflection that actually comes to the point in her own experience. She doesn't give the point of the story in full, but in small bits over the course of the larger story. Key phrases are "I will do it"; she says this twice. The point: She wants us to know she is capable, and can do 'most stuff' but patience and understanding will assist those asking her to do things to temper their expectations of her walking, coaching, working, etc. This story is sort of a chaotic narrative; in original form; it was difficult to see through to the main idea. One of the first things I did was to 'clean up' the story, removing some lines and some of the interviewers words of encouragement, mostly paralinguistic "Yes, Yup, OK" throughout the transcript. A few times in the larger interview and during the art exercise she stated she has difficulty "getting my ideas out". The use of examples, ending in reflections and her points, were useful in allowing her to relay her story. The structured form of her story telling works for her in relaying her main points and thoughts about the lack of understanding from others, and the invisibility of the disease. The verb tense she uses is recent past, present, and one example of distant past (young with her arm in a sling). Tensions were set up frequently, for example, her boss and uncle's understanding contrasted with the soccer organizers lack of understanding, and her families history of arthritis showing signs in their 30's and 40's juxtaposed with her early onset. The universal story structure is tragedy/satire. There is a sharp, somewhat frustrated tone here, but there are small amounts of humor: "...don't expect me to kick the ball...especially with a bunch of kids in cleats [laughing]"; "...it's not something I wanna---tell the world. Like, 'oh, I have arthritis, so---you know' ". This story can

be summed with, "I just want somebody to understand I will do it, it will take me a little bit longer, but I will do it".

"The hardest part is the emotional part: not playing soccer with and worrying about my sons"

The main function of this story is describing the "hardest things...the emotional part that goes with the whole thing". The 'whole thing' is doing what she has to do, as affected by arthritis. She tells two stories in one. The first is about participating in soccer and biking with her family, the second is about how she worries about her sons, and how she might mediate what they know about arthritis, as "there is probably a lot going in their heads that they don't talk about."

As with the previous story, this story uses examples followed by reflection, but more straightforward. In the first story, she says "My husband even goes, 'Honey, I wish you could play soccer with us'. So do I. ...and worst of all is feeling really awful---I was on the couch once for two days. Pain. But that's the hardest part for me". She then moves on to how this affects her active participation: "And they [sons, 7 and 10] were both in soccer, but get them to do that---but you do what you see". She follows by saying that although they have bikes, and they can ride, then "...it's OK and sit down and chill out and---but unfortunately, it's what you got to do". She seems to be telling us that her level of participation when she needs to be resting may affect how her sons participate.

The second story she relays her fears of her sons having arthritis due to her family history, but she is "worried about them". However, "...I know what to look for, thank goodness. And we will catch it right away. Hopefully, it won't affect them. It's one of those things". She continues by saying her sons have "never known me as being under control...I don't overdo it, even though you're in bed, just like anybody with any kind of problem...but I'm pretty lucky that they're older---most people curl up on the couch with an icepack---they're there. It's kind of us. There is probably a lot going on in their heads that they don't talk about". She is concerned about allowing them the venue voice these concerns, and feels her older son can attend the doctors with her, as her experience with her fairly doctor

is positive: "He is fabulous. He doesn't talk to me about the kids, he talks to the kids with me in the room...it's wonderful...he's very patient". She relays their past talk about tried and central medical options based on their visit to the doctor about warts on her sons feet. She believes that involving her son in the physician's visit may assist in him respecting the process of going to the doctor for answers, "...He likes going to see the doctor and being able to ask all these questions" and may assist in giving him answers about her arthritis: "Cause I think taking him with me, he will—if he is worried or there are fears or concerns that they'll be kindov squashed". What this story revealed about her circumstance: The emotional part of being unable to participate and worrying about her children's understanding of the disease, and how her lack of participation hinders her ability to encourage them to participate is difficult. The story was told with a sense of concern, and with a strategizing tone in the second part. The tensions were set up with her description of being on the couch with her sons there, juxtaposed with her wish to be involved and encourage her sons. The strategy she uses are many examples to relay these thoughts, as in the story of her sons at the doctors, how this was helpful, and how she may be able to use a similar setting to in the future to address how they may be able to better understand the arthritis. Striking vocabulary includes "the hardest", "You do what you see", "It's what you got to do", "hopefully it won't affect them", "It's kind of us", "Hopefully it won't affect them", "If he is worried or there are fears or concerns that they'll be kindov squashed". The universal story structure is tragedy (first story) and moralistic tale (doctor story). Her character portrayal is tragic and hopeful. Key mood setting vocabulary includes "I wish", "Feeling awful...pain", "unfortunately", "hopefully", "It's one of those things". There is a sense of being unable to do a lot; or being in a circumstance without choice; this makes sense from the constraints she has: her husband is out working most days and evenings as a plumber and a volunteer fire fighter, she works 30 hours a week, and is responsible for all of the housework and much of the childcare. Her in-laws live next door but are of little support. In another story, the theme is support

would be nice, but I do what I need to do, on my own. These constraints probably add to the feeling of just getting through every day.

Appendix I

Participant data analysis flow charts

