


Living in the Present: Women's Everyday Experiences of Living With Rheumatoid Arthritis

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Abstract

This article presents the findings from a qualitative research project exploring eight women's experiences of living with rheumatoid arthritis (RA). Through semistructured interviews, the women provided insights into the physical, emotional, and social impacts of RA and the "work" involved in negotiating its influence in the everyday life. In narrating their experiences of adapting to RA, the women express a common desire for "normalcy," to return to a time and space before the disruption of RA. The women's accounts also emphasized the interrelatedness between bodily experience and constructions of self, highlighting the corporeal nature of RA and the constant shaping and reshaping of personal meanings and values.

Keywords

arthritis, disability, lived body, women, qualitative research

Introduction

Traditionally, understandings of chronic illnesses such as rheumatoid arthritis (RA) have been dominated by a singular focus on physical symptomology and treatment options (Harrison, 2003; Reinseth & Espnes, 2007). In the early 1970s and 1980s, medical sociologists such as Friedson (1970) and Bury (1982) challenged this biomedical focus, asserting the need to understand chronic illness as both an embodied and lived experience. Theories of embodiment and lived experience conceptualize the individual with RA as an active agent who routinely makes sense of themselves and their condition within the context of their everyday lives (Burr, 2003). This engagement with the subjective disrupts the "objective medical gaze" and repositions the individual as a key "player" in the meaningful renegotiation of "who they are" and "what they do" (Christiansen, 1999; G. Williams, 1984). Within this framing, the individual with RA is no longer subsumed by the physical impairment (Goodley, 2012).

Drawing on disability studies and its intersections with postmodernism, allied health professionals and social researchers influenced by this philosophical shift have reoriented their practice from an understanding of the body as impaired, to that of the body as "irreducible to impairment" (Hall, 2011, p. 1). This critical understanding challenges the focus on the "disabled body" and instead (re)presents disability as "the space from which to think through a host of political, theoretical and practical issues that are relevant to

all" (Goodley, 2012, p. 632). In practice, it means adopting a person-centered approach in which the client's voice and experience is privileged (Alsaker & Josephsson, 2003; MacDonald, 2008). The emphasis on the "client's" voice resonates with postmodernism's valuing of both "situated" (Haraway, 1988) and subjective knowing (Trevithick, 2008) vital to personal empowerment. This situated knowing is also, as MacDonald (2008) suggests, integral to the collective empowerment of people living with chronic illnesses such as RA and the understandings of the broader community; the "experiences/stories of people with (dis)Abilities and sufferers of chronic pain need to be welcomed into the discourse on chronic pain, a discourse that has been predominately occupied by biomedicine" (p. 138).

Within this broader framing, allied health professionals relinquish traditional concepts of adaptation and adjustment which draw on normative assumptions of disability and ability. Within a multifaceted understanding of RA, the professional–client relationship is informed by and "adapted to the everyday realities of individual's lives" (Plach, Stevens, & Moss, 2004, p. 138). The health professional's role is primarily one of

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actively supporting the individual's process of rethinking taken for granted assumptions and behaviors and reattributing meaning to everyday activities and roles (Hyden, 1997; Nyman & Lund, 2007). In this process, professional skills are used to "reframe the sufferer's [*sic*] situation, to reduce self-blame, validate the sufferer, provide a critical lens to their . . . experiences" (MacDonald, 2008, p. 138). Integral to the rethinking and reframing of lived experience is a corresponding need to engage with the socio-emotional experiences of living with RA. However, as consumer research consistently reports, specialist wait times in combination with the short duration of appointments mean that "there was never the time to talk about anything other than the physical symptoms" (Brand, Claydon-Platt, McColl, & Bucknall, 2010, p. 79). As Brand et al. (2010) report, "Important topics that caused anxiety, such as the long-term impact of RA and prognosis, were reported to be inadequately discussed" (p. 79).

Engaging with the theory and practice of these understandings within the context of this study allows for a new exploration of the everyday negotiations and adaptations of eight women living with early-diagnosed RA. The women's accounts provide a nuanced understanding of RA and its disruptive effects within their physical, emotional, and social lives. The emphasis on "normalcy," the impact of uncertainty, the focus on the body, and the contentions relating to adaption and adaptation provide examples of the multifaceted approach taken by the women to remake themselves. In describing these processes, the women narrate their social and emotional experiences of "adapting" to RA, their negotiations of the negative thoughts threatening to overwhelm, and the energy required to "keep positive." The women's accounts are also a reminder of the deeply felt impacts of RA making it a "less 'liveable' condition" than other chronic illnesses (Wiener, 1975, p. 98).

Literature Review

Clinical Description

RA is a chronic inflammatory disease affecting 0.5% to 1.0% of adults in developed countries and is three times more frequent in women than men (Scott, Wolfe, & Huizinga, 2010). Prevalence rises with age and is highest in women older than 65 years, suggesting hormonal factors could play a role (Scott et al., 2010). The prevalence for Sweden is 0.8% (Neovius, Simard, Askling, & ARTIS Study Group, 2011). Patients are diagnosed across all ages and the mean incidence ages vary between 56 and 58 years (Thyberg, Dahlström, Björk, Arvidsson, & Thyberg, 2012; Verstappen & Symmons, 2011). The introduction and use of pharmacological treatments in the early stages of the condition in combination with new biological drugs have led to reduced disease activity and less disability (Scott et al., 2010; Sverker et al., 2015). However, RA is still associated with disabilities and reduced quality of life (Söderlin, Lindroth, & Jacobsson,

2010; Sokka et al., 2009; Thyberg et al., 2012; Ziegler et al., 2010). Women in particular are identified as experiencing higher disease activity and pain and more difficulties in performing daily activities than their male counterparts (Ahstrand, Bjork, Thyberg, Borsbo, & Falkmer, 2012; Sokka et al., 2009).

Chronic Illness as Disruption

In his research exploring people's experiences of RA, Bury (1982) makes the following statement: "My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (p. 169). This notion of disruption is emphasized in Scambler and Scambler (2010) who interpreted chronic illnesses as "assaults on the lifeworld." As an assault, chronic illness is a jarring intrusion within the context of people's private and public lives, it is uninvited and unwelcome (Nyman & Lund, 2007). The presumed assumptions that assist in directing everyday life to ensure that it is predictable and certain are no longer appropriate, relevant, or useful (S. Williams, 2000). The tacit knowledge that allowed mastery within the everyday life is suddenly irrelevant and meaningless (Bury, 1982; S. Williams, 2000). Activities, roles, and functions that structured everyday life and shaped people's perceptions of themselves and their relationships with others were in disarray (Iaquinta & Larrabee, 2004). The disruption to the performance of activities done routinely could engender feelings of anger, fear, frustration, self-consciousness, and depression (Alsaker & Josephsson, 2003). While such emotions can be "healthy" within processes of renegotiation, longer term experiences are generally detrimental to the person's self-concept and relationships with others (Iaquinta & Larrabee, 2004, p. 283).

Uncertainty

Uncertainty and unpredictability are common features in the experience of chronic conditions such as RA. While uncertainty is often referred to in the context of the physiological manifestations of RA, its definition and implications are far wider. As is documented across the research literature on RA, uncertainty plays a key role in shaping a person's everyday understandings and experiences (Bury, 1982; Flurey et al., 2014; Lööf, Johansson, Henriksson, Lindblad, & Bullington, 2014; Strauss et al., 1984; Wiener, 1975).

Published in the mid-1970s, research by Wiener (1975) provides an introduction to the uncertain realities of people living with RA. Wiener's research linked uncertainty to social and psychological well-being and described the psycho-social strategies people adopted "when uncertainty is exaggerated beyond the usual level of toleration" (p. 97). Wiener locates uncertainty as inherent within the physiological impacts brought on by RA, including flares, and the

general interruption/disruption to everyday life. Coventry, Dickens, and Todd (2014) also highlight the pervasiveness of uncertainty in the RA experience describing their research participants as living “in a perpetual state of uncertainty” (p. 113). Strauss et al. (1984) identify uncertainty as a powerful mediator of people’s constructions of an embodied self. Uncertainty could engender a range of emotional and psychological responses including feelings of fear, dread, and frustration (Coventry et al., 2014); anger and helplessness (Löf et al., 2014); and outcomes of depression and anxiety (Flurey et al., 2014). For Wiener’s participants (and as is recognized in more recent research), a return to “normal” life and functioning underpins the strategies they developed and adopted; “success” is achieved when a person feels they can “tolerate” the uncertainty and unpredictability of RA on any particular day or hour.

Bodily Experience

Within disability studies, “the body” has been and continues to be constructed and reconstructed according to shifts in discourse and power. Goodley’s (2012) overview of disability studies draws attention to the “role” of the body within conceptualizations of impairment and disability. Traditional framings of the body as a site of impairment were challenged by sociological analyses in which “having an impaired body did not equate with disability” (Goodley, 2012, p. 634). This separation between the biological (physical) and the social was problematized by people whose lived experience of impairment—the physical and/or biological constraints—shaped and informed the meanings they made of themselves and their lives (Crow, 1996; Wendell, 1996). While advocates of feminist disability studies supported the notion that the “impaired body had been neglected” (Crow, 1996; Meekosha & Shuttleworth, 2009, p. 59), their interpretation of impairment moved from “specific forms, functions and behaviours” to an engagement with corporeality and the “intricate relation between bodies and selves” (Garland-Thomson, 2005, p. 1557). In this vein, contemporary feminist disability activists including Inckle (2014) engage with the notion of “disabled embodiment”: “a dynamic, lived position that intersects mind, body, emotion, social, self and other, and operationalises new and challenging forms of representation and articulation” (p. 389). Both corporeality and embodiment speak to the complex realities of many women living with chronic illness such as RA, whose social and emotional well-being alongside their personal and public selves are routinely shaped by the physicality of their condition (Ahstrand et al., 2012; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004; Plach et al., 2004).

The notions of embodiment and corporeality also acknowledge the body as gendered. For feminist disability advocates, this facilitates the “interrogation” of patriarchal scripts of femininity and in particular, constructions of the “ideal female body” (Inckle, 2014). As is clearly identified

within feminist disability studies, women with a disability are not immune to these dominant constructions and the broader discourse relating to what Garland-Thomson (2005) describes as the “politics of appearance” (p. 1559). The rigid descriptions of how and what women “should be” reinforce the traditional binaries between the normal/abnormal, abled/disabled, and desirable/undesirable. As Peuravaara (2013) explains, “Conceptions of bodily normality constantly exist as a ‘measuring stick’ . . . as a woman . . . you are never ‘free from’ images of bodily normality” (p. 412). As Shildrick (2007, p. 222) asserts, “Corporeal difference” is not part of the idealized female body, nor is it considered as constitutive of an active sexual subjectivity. Within these interpretations, the disfiguring and disabling effects brought on by RA position women as the “Other” both in terms of femininity and sexual agency (Plach et al., 2004; Shildrick, 2007; S. Williams, 2000).

Opportunities for Transformation

Opportunities for renegotiating relationships with others or learning different ways of performing activities can provide spaces for people with RA to “assess and expand their construction of themselves and their illness and . . . search for alternate realities” (Kelley & Clifford, 1997, p. 276). This discovery of other ways of “being in the world” can be epiphanic leading to what G. Williams (1984) describes as a process of “narrative reconstruction.” This process of re-storying can be empowering and emancipatory, providing alternate understandings of self and the roles assumed in private and public life (Plach et al., 2004). For Dubouloz et al.’s (2004) re-storying is an example of the type of transformative learning, possible for people experiencing chronic illness. Similar to Carel’s (2007) theorization of RA as transformative, it is proposed that the disruptive nature of RA within people’s everyday performance of activities and tasks can be mediated by a “transformative” shift in the person’s meanings, values, and knowledge. Through a process of critical reflection, involving the deconstruction and reconstruction of previous life stories, a new identity can be formed allowing the person to achieve the balance necessary for maintaining health and well-being (Carel, 2007; Dubouloz et al., 2004). It is important, however, to recognize that such transformations and reconstructions occur within a broader political and social context.

Negotiating Assumptions Within the Social Context

The bodily experience or corporeality of RA intersects with dominant constructions of disability (Thomas, 2007). While contemporary understandings of disability have challenged both the primacy and authority of medicalized discourses, deficit-oriented subjectivities continue to be imposed upon people living with chronic illness (Goodley, 2012; Snyder &

Mitchell, 2006). Goodley (2012) draws attention to the narratives “manufactured by charities, science and popular culture” through which disability is defined as a “personal tragedy, biological deficiency and psychical trauma” (p. 3). Within these scripts, the person becomes and/or is consumed by the physical; meaningful engagement with the broader social, economic, political, and cultural context is discounted. According to Goodley, such narratives “*dis-locate disabled people*” (italics in original) both in materialist and cultural terms (p. 3). Snyder and Mitchell (2006) agree, identifying “social erasure” as a possible outcome of these public narratives; “disabled citizens are forced to exchange their liberty for necessary (and unnecessary) social supports” (p. 19). Thomas (2007) concurs, describing the social exclusion and restrictive citizenship produced through the dominant narrative as “a form of social oppression involving the social imposition of restrictions on people with impairments and the socially engendered undermining of psycho-emotional well-being” (p. 73).

Negotiating the Everyday

Traditional understandings of adaptation emphasize the person’s capacity to function and perform activities and roles within their everyday lives (Reinseth & Espnes, 2007). Negotiating the challenges of living with RA can be a physically and emotionally exhausting process whereby functioning and performance can become measures of personal defeat and bodily deficit. Kelly and Field (1996) describe the impact of such traditional interventions in their narrative research with people experiencing fibromyalgia: “The symptoms have taken over the person’s life creating a problem-saturated life story in which other elements of the life are ignored” (p. 266). According to research by Schulman-Green et al. (2012), narrow conceptualizations of adaptation are problematic in their focus on the functional and physical aspects of people’s experiences, marginalizing the “importance of emotional and existential processes, such as reconciling emotions and deriving meaning from the illness experience” (p. 137). Thus, adaptation becomes a process which facilitates people’s capacities to respond meaningfully to challenges and achieve a state of well-being through their everyday activities.

Theoretical Framings, Methodology, and Methods

This research sought to explore women’s experiences of living with RA, with a particular focus on their engagement with everyday activities and roles. In undertaking this exploration, the researchers adopted a qualitative methodology and postmodern framings relating to subjectivity and context. As a condition that predominantly affects women the researchers were cognizant of the intersections between gendered subjectivities and everyday

practices (Olesen, 2011). The focus on understanding the subjective experiences of women with RA resonates with the postmodern framing of the person as an active meaning maker who, through their interactions with others, routinely construct and reconstruct understandings of their self(ves) and their realities (Burr, 2003). These understandings are fluid and dynamic, responsive to new information and environments. This impermanency produces the capacity for change: a poignant factor in this study of women whose everyday lives demanded ongoing change (Lempp, Scott, & Kingsley, 2006). In exploring women’s lived experiences of RA, the findings of this research contribute to the broader shift in research by documenting the experiences of the “viewpoint of ‘insiders’ who live with RA day in and day out over decades of their lives” (Plach et al., 2004, p. 138). Within a qualitative approach, researchers attempt “to make sense of, or to interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2005, p. 3).

Setting

The eight women who participated in this research were recruited from the prospective multicenter research project Early Interventions in RA (Swedish acronym TIRA). The TIRA project aimed to establish clinical routines for early RA diagnosis and early multiprofessional interventions. A database for research was also established (Thyberg et al., 2012; Thyberg, Hass, Nordenskiöld, & Skogh, 2004). Selection in the broader TIRA-1 cohort was based on gender (being female), age, living with RA, and, for practical reasons, resident in Linköping, Sweden. For this research project, a purposive sampling framework was used to identify potential participants: women who were under the age of 40 years and living with a diagnosis of RA. From the TIRA client records, 13 women were identified as potential participants for the study. An introductory letter that included participant information was mailed to each of the potential participants. A follow-up phone call was made 1 week later by the researchers with the aim of responding to any questions the potential participants might have and to ascertain participation. Of the 13 women invited to participate, three women declined citing reasons of being “too busy” and two were “not having any symptoms.” Eight women agreed to participate in the research. While aware that eight participants was a small sample, a larger sample would have required recruiting women from the middle-age bracket and changing the aim of the study. The local ethics committees of all the participating units in Linköping, Västervik, and Norrköping approved the studies prior to data collection and ethics approval was given (Approval number 96035), and each of the participants gave their written informed consent. The interviews were performed during the women’s 5- and 7-year follow-ups in the TIRA study.

Table 1. Participant Demographics ($n = 8$).

Participants	Demographics at time for interview		
	Age	Employment	Family context
1. Eva	43	Full-time	Partner, one teenager
2. Anna	24	Maternity leave	Partner, two children
3. Ingrid	40	Part-time	Single, two teenagers
4. Brigitta	27	Full-time	Single, one child
5. Mikaela	26	Full-time	Partner, pregnant
6. Kristina	34	Part-time	Partner, one child
7. Maria	38	Full-time	Partner, two teenagers
8. Monika	39	Part-time	Partner, two children

Introducing the Participants

The eight women interviewed for this research were aged between 24 and 43 years, the median age was 36 years. Table 1 identifies each participant by pseudonym (used in the findings and discussion), alongside her age, employment status, and family context. All the women were employed full-time, with one woman on maternity leave. Six of the women identified that they had partners. At the time of the research, one woman was pregnant and the remaining seven women had children aged from babies to teenagers. In the clinical appointment prior to the interview, the women completed a disability assessment using the Swedish version of the Health Assessment Questionnaire (HAQ) and a pain assessment using the Visual Analogue Scale. The women reported low to moderate scores for both disability and pain.

Data Collection

In keeping with the qualitative methodology framing the research, semistructured interviews were undertaken with eight participants. Constructed as conversations between the interviewer and participant, the in-depth interviews focused on exploring the meanings and knowledges made by women with RA as they negotiated their everyday lives (Fontana, 2001). The use of a conversational approach to interviewing enables us to "... know other people, get to learn about their experiences, feelings, hopes and the world they live in" (Kvale, 1996, p. 5). An interview guide (see Table 2) consisting of open-ended questions was developed, drawing on the literature relating to the lived experience of RA and in keeping with the aims of the study. Through this process, two groups of questions were developed as a guide for the interviews: (a) the meanings women make of their experiences of living with RA and (b) the ways women negotiated the everyday realities of living with RA. With an emphasis on ensuring that the women felt safe and at ease, the interviews were conducted at either the woman's home or the rheumatology clinic, and at a time that was convenient to each participant. The interviews were between 35 and 80 min duration and were audiotaped.

Table 2. Interview Guide.

<i>Exploring everyday life:</i> Describing a "typical" day; impact of RA in everyday life; perceptions of ability and capacity to perform everyday tasks and activities; meaning in everyday life—changes, new found meanings.
<i>Relationship with/to body:</i> Perception and experience of bodily changes; meanings made of these changes; practical impact of bodily changes in activities and routines of everyday life.
<i>Adaptations:</i> Changes made to facilitate performance of activities and tasks; meaning making of changes; experience of adaptations made.
<i>Family and friends:</i> Understandings of family's perceptions of RA; impact of RA on family members; negotiations with family—distribution of activities and roles; changes to these? <i>Friends:</i> Disclosure to friends; perceptions of friends' understandings of RA; practical, emotional, and social support?
<i>Relationship to self:</i> Understanding of self prior to RA and now; identifying impact of RA on self and identity.
<i>The future?</i> Opportunities, changes, concerns, potential barriers.

Note. RA = rheumatoid arthritis.

Interpreting the Interviews

Informed by the postmodern emphasis on "many ways of knowing" (Denzin & Lincoln, 2005), data analysis was undertaken by the interviewer-as-researcher through a process that "emphasises descriptive nuances, differences and paradoxes" (Kvale, 1996, p. 226). The audiotaped interviews were transcribed verbatim and each interview was subject to several close readings before any formal interpretation commenced. These readings facilitated an immersion in the interview data and, as Green et al. (2007) suggest, "allows a detailed examination of what is said and stimulates a process where one begins to 'incubate' ideas about the possibilities of analysis" (p. 547). After these initial readings, each interview was subject to a process which Ely, Vinz, Downing, and Anzul (1997, p. 206) describe as "sorting and lifting" of "words, sentences or paragraphs containing aspects related to each other through their content and context" (Graneheim & Lundman, 2004, p. 106). The meaning units were then categorized according to their descriptive content and formed into themes, overall understandings of a particular issue, idea, or experience. This interpretive process was repeated, allowing for the emergence of further similarities, nuances, divergences, and differences within and beyond these initial categories (Green et al., 2007).

In acknowledging that qualitative data analysis is an interpretive process whereby researchers construct an interpretation of what the data may mean, infer, or represent (Denzin & Lincoln, 2005, p. 3), it is important to ensure the "quality" or trustworthiness of the material produced through analysis (Graneheim & Lundman, 2004). During analysis of the units, themes and categories emerging from the material were discussed by two other members of the research team as a means of increasing the credibility and trustworthiness of the material (Graneheim & Lundman, 2004). The analysis process

also involved reading back and forth between the interview data and each meaning unit, theme, and category to ensure that the material in each was appropriate and that all relevant data had been included. The “Findings” and “Discussion” sections in this article use direct quotes from the interviews. Within the paragraph, direct quotes are italicized and encased with double quotation marks. Participant is identified by pseudonym, as presented in Table 1. Block quotes are also used in the text; these are indented from the margins. Direct quotes are a way of reaffirming the relationship between the participants’ stories and the interpretations offered in this article.

Findings

“Being Normal”

The unpredictability of chronic conditions such as RA was described by the women in this research as one of the more difficult and frustrating aspects of their experiences. The continuum of physical symptoms from periods of remission to the intense pain and incapacity of flares were a persistent reminder of their disability and a barrier to “being normal.” The seeming randomness of symptoms and the onset of flares could make it difficult, if not impossible, for the women to participate in the routines of daily life. As one woman lamented, the “normal” tasks she performed in caring for her family, such as doing the laundry, cleaning the house, making dinner and taking care of the children after work, were now both time-consuming and an inefficient use of her time and energy; *“you have to slow down all activities. If you had been well, it would have been possible to speed it up”* (Kristina) to get things done on time. Plans made ahead of time could be made redundant by the onset of pain or fatigue. Similarly, for some of the women, the sudden onset of symptoms had meant the disappearance of spontaneity from their lives. In this context, the desire for normalcy, for “being normal,” was identified by some women as both a “wish” and a strategy for negotiating the impacts of RA.

While the notion of “normal” is contested within the broad landscape of disability studies, the women’s descriptions of “normal” can be interpreted as a metaphor for a time and space before RA. For some of the women, “being normal” was related to having control within their daily lives, the capacity to “do what everyone else does” (Ingrid), and to return to “business as usual” (Monika). Normal was about being able to engage with activities and roles previously taken for granted, from going to the gym and exercising like other patrons to managing the same assignments as colleagues in the workplace.

From listening to the women’s accounts, it was clear that “being normal” was easier to achieve during periods free from pain and joint stiffness, when the impacts of the condition were minimized. During these times, it was possible to engage in everyday activities, roles, and tasks both within the home and at work, without the need for adaptations, such as,

the use of assistive aids or supports. Achieving normalcy on a longer term basis however required a more comprehensive strategy of adjustment. This involved engaging with accessibility and assistive aids and the ongoing evaluation of the meanings and values of particular activities and roles.

Adaptions for “Being Normal”

For many of the women, “being normal” required that they learn to minimize the impacts of RA in their everyday lives. Key to this was the issue of adaptation. Perhaps because of its centrality, adaptation proved to be a contentious and complex process, embedded within the women’s broader understandings of what it means to be “normal” and how “normal” could be achieved. While each of the women had made some adaptations to the activities and tasks they performed in their daily lives, the type and form of adaptation made was shaped by the meanings the women made about RA as a physical, emotional, and social experience. Adaptations could also be time specific, adopted within a particular context such as a flare and then abandoned after the flare had subsided. These temporary adaptations were key strategies in some of the women’s negotiations of RA, facilitating a return to the “normal” as soon as was practicable.

Adaptations that could easily be incorporated into a current routine were regarded as positive: The women provided examples of lifting an item using two hands instead of one, placing heavier objects on a lower shelf in the kitchen, and performing labor-intensive tasks in stages. Seven of the women identified using disease-modifying anti-rheumatic drugs (DMARDs) as part of their adaptation to RA. These medications are identified as “key therapeutic agents, reduce synovitis and systemic inflammation and improve function” (Scott et al., 2010, p. 1100). Other adaptations identified by the women related to prevention strategies, such as minimizing the impact of particular activities on the body. While acknowledging prevention as an important strategy, one woman described how difficult it was to think about prevention or as she states, “sparing my body” in pain free times;

The occupational therapist I met told me to avoid carrying heavy bags and to take the trolley when shopping for groceries, but I’m the kind of person that takes a basket and fills it up so much that I (can) barely manage to carry it and then, at that point, I think it’s better for me to use a trolley instead, to save my hands. I try to remember her advice but, I want to do it myself and I’m too stubborn in that situation, I think. I don’t think that much about sparing my body. (Monika)

Some adaptations identified by the women were less tangible and involved the reshaping of household roles and responsibilities for family members, friends, and/or work colleagues where these parties had been informed. This was particularly evident in the women’s accounts of flare where family and friends provided practical support in performing everyday tasks. In some instances, the need for adaptation led

to role changes within the family, with partners, children, and/or a parent taking on domestic activities. One woman describes calling on her mother in negotiating care for her baby;

When my first (child) was a baby was the worst time because my partner worked nights so my mum had to come home to change (nappies) at night and things like that. (Anna)

Ambivalence About Adaptation

For some women, adaptation represented a life regulated by their disability and a threat to “being normal” and how they conceptualized themselves. These women were ambivalent about their engagement with assistive aids and adaptation more broadly. A number of women described being prepared to negotiate pain and discomfort rather than adapt. One woman’s desire to be a “real mum” shaped her attitude toward adaptation. For this woman, adapting to RA challenged the authenticity of her role as “mum”; “I want to be a real mum. I put that before adaption to the disease” (Brigitta). Another woman described the “informed choice” she made in continuing to ski despite knowing the consequences: “I do what I think is fun . . . I go skiing a lot . . . I know it (RA) will get worse in the evenings. I know I will get more pain” (Mikaela).

For some of the women, assistive aids were a symbol of their disability, an unwelcome reminder of the disabling impacts of RA and their decreasing physical capacity. While using assistive aids in the workplace, one woman described her reluctance to use domestic aids, such as a cheese slicer, which she identified as reinforcing her “impairment” and threatening her efforts to be “normal”:

In my job I have pencils with a rough grip, but other things feel, no cheese slicers and things make you feel so handicapped, whereas in fact you want to try to live as normally as possible. (Kristina)

Some of the women also identified the risks involved with adaptation. Changes to activities including the way in which they were performed could change the meaning of the activity and its significance. One woman describes her previous participation in taekwondo and aerobics, intensely physical sports which she can no longer undertake. While emphasizing the importance of exercise as a way of mediating her RA, the new activities she had adopted were less meaningful;

It is good to exercise when you’ve got rheumatism. You should exercise every day. You can do activities like walking, cycling, swimming, but in fact I really find them boring. (Brigitta)

Who Am I?

In their discussions of RA as a lived experience, the women reflected on how the physical experiences had shaped their understandings of “self” and of “self in relation to others.”

For some of the women, their experience of RA had profoundly altered their sense of self, as one woman comments, “I’m no longer the kind of person I once was and want to be” (Brigitta). This powerful statement suggests a clear line being made between a pre- and post-RA self, possibly extending to a future self. Other women used specific adjectives to identify the personal impact of RA, describing themselves as “more negative” (Eva), “boring” (Brigitta), “more sulky” (Maria), and “more bad tempered” (Kristina). The use of “more” in the above phrases again reflects the notion of a pre- and post-RA self, with the experience of RA exacerbating their pre-RA responses. Some women described themselves as having become “introverted and retiring” (Brigitta). One woman described herself as more negative and sulky, a way of being which influenced the experiences of other family members:

You become more, get a more negative attitude [toward activity] you think it’s kind of boring and that also influences everyday life, and other family members also think it’s hard, boring. Maybe you become more sulky, so to speak, you think it’s a pain and then the others also get affected. (Maria)

The Body as Self

The physicality of RA, the pain, stiffness, and the swelling of joints was described by some of the women as shifting the body from the margins of self-concept to the fore. This was expressed in a number of different ways, with some women identifying an emotional distance between themselves and their bodies particularly during flares. One woman described this separation in terms of “not belonging with the disease” (Brigitta) and expressed feeling “like another person in flare ups.” Other women spoke of feeling consumed by their bodies. One woman described “thinking about (her body) all the time,” especially during physical activities such as walking or vacuum cleaning:

Yes I think a lot about my body, for example when I vacuum clean. That is almost one of the worst things or when I go for a walk or something, all the time I’m thinking about my arms. I feel that I always worry about it. I think about it all the time. (Maria)

Creating a Positive Self

Besides these difficulties, some of the women described positive shifts in not only how they understood themselves but also how they engaged with and made sense of others in the world. One woman felt she had become a “stronger person,” who “knew how to handle difficult situations and no longer complained about minor things” (Eva). Another woman identified having developed greater empathy for people. For this woman, the experience of RA had broadened her awareness and understanding of other people’s experiences:

Actually you become hardy in another way, and then it’s easier to understand other people too. Maybe they don’t understand

me, but it becomes easier to feel empathy for others when you are feeling bad yourself sometimes. (Anna)

For one woman, the use of supports such as assistive aids had allowed her to gain control in her everyday life. Instead of permanently adapting to an activity, this woman would use physical aids and ask others for help when she decided she wanted support. For this woman, RA was not all-defining, rather as she asserts, “the disease has had to adapt to me a bit” (Mikaela).

Emotional Fallout

The emotional journeys recounted by the women in this research highlight the subjective and inherently personal impacts of RA. Feelings of anger, sadness, and frustration were recounted by the women as they negotiated the emotional fallout from their experiences of living with RA. As one woman explained, “Sometimes it was easy to think negative thoughts,” to question “why me? This is unfair” (Maria). The women also spoke of their capacity to renegotiate the position of RA in their understandings of self. One woman referred to this capacity as “putting the problem behind me” a way of sidelining the impacts. While acknowledging the difficulties of this process, one woman was adamant about the need to “think positive thoughts and try to find possibilities instead of dwelling on the problems” (Anna). Drawing on a similar strategy, another woman spoke of her need to keep both her emotional and physical life in balance so that the “condition did not take over.”

Some of the women spoke of coming to terms with their experiences, accepting the circumstances and increasing their awareness of the possibilities of a life with RA. Some women also spoke of the importance of learning to be honest with themselves within this process of acceptance: honest about their capacities, about “lowering demands and setting up realistic goals.” One woman describes as follows:

You have to admit to yourself that you can’t manage all this, that you can’t put too many demands on yourself because then you just feel worse. No, my mental adjustment has been to set up realistic goals that I know can be reached, and not say I want to do this and that and then never do it. (Ingrid)

This notion of “learning to live with RA” referred to the constant evaluation of everyday life, not only in terms of the tangible but also about what was meaningful and valuable for each of the women. For many of the women, sharing their diagnosis and the experience of RA with family and/or friends was fraught with competing emotions. Reluctance to talk with family and/or friends about RA was explained by a desire to maintain independence and autonomy, fear of being cast in the “sick role,” and of not being believed or understood. For one woman, this reluctance was heightened by her experience of being “treated with suspicion” by her work colleagues when she was not able to perform an activity: “That is what is most sad, that people . . . that this is a disease that no one can see and so they don’t believe you” (Anna).

Discussion

Re-Storying the Self and Others

Contemporary explorations of the lived experience of chronic conditions such as RA highlight the ways in which people re-author their lives in the context of disability, creating new ways of understanding themselves and their relationships with others (Reeve, Loyd-Williams, Payne, & Dowrick, 2010; Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015; Sanderson, Calnan, Morris, Richards, & Hewlett, 2011; S. Williams, 2003). Within the context of this research, each of the women identified moments which reflect aspects of Bury’s (1982) concept of “biographical disruption.” The lived experience of RA, the fluctuations in physical and emotional capacities, had undermined the authority of the taken for granted assumptions and explanatory frameworks they relied on for a sense of “self in the world” (Bury, 1982; S. Williams, 2000; S. Williams, 2003). The disruption was personal, affecting their understandings of self, the meanings they made of the roles, and activities and tasks they performed in their immediate and broader contexts. Dubouloz et al.’s (2004) research focusing on the meaning constructions of people with RA reported similar findings, with participants describing experiences of being “redefined by illness” and an overwhelming sense “they could not control the illness but were controlled by it” (p. 401). Alsaker and Josephsson (2003) provide similar evidence suggesting that the unpredictability of RA can create a space of suspense in which people experience an ever-present fear of “getting stuck” (p. 174). Personal identity and self-concept which had once been stable were now in flux, fragmented, and disjointed; meanings of self in the world were subject to the uncertainty of the condition. There was an expressed desire to return to the known self, “the person they used to be.” Such sentiments echo with Plach et al.’s (2004) research with women living with RA, who described themselves as “out of synch with who they had been . . . [and] . . . with who they had thought they would become in the future” (p. 145).

The concept of biographical disruption although important is not without critique and a closer reading of the women’s accounts highlights the need for more complex and nuanced understandings of living with RA and its “disruptive” effects within everyday life (Reeve et al., 2010). Contemporary conceptualizations of the self as an embodied and active agent challenge the notion of disruption as all-consuming and permanent (S. Williams, 2003), reflecting Sanderson et al.’s (2011) proposition that “biographical disruption may form only one part of a person’s multilayered illness narrative” (p. 630).

The postmodern understanding of self were fluid and dynamic, embedded in context, offers an alternate account to the coherent and stable self, evident within biographical disruption (Carel, 2007). The women in this research actively negotiated and re-negotiated domestic and work routines

alongside their interactions and relationships with family and friends (S. Williams, 2000). These negotiations were not only practical in their focus but also often entailed a fundamental rethinking of meanings made and values held. Sanderson et al. (2011) describe this re-framing of self as a form of narrative reconstruction, a process of creating “points of reference between the (changed) body, self and society, reconstructing the past so that it has meaning or purpose for the present” (p. 619). The process is dynamic and open, allowing for “the weaving of “new symptoms, new knowledge of the condition, and new reactions from others into the story” (Sanderson et al., 2011, p. 619).

Similarly, contemporary conceptualizations of chronic illness as an embodied or corporeal experience challenge the “over-emphasis on a cognitive view of the self” within biographical disruption (Reeve et al., 2010; S. Williams, 2003). The relegation of the body to the margins is at odds with the lived experience of RA (Reeve et al., 2010; S. Williams & Bendelow, 1998). The physicality of RA, the fluctuating periods of flare and remission alongside the everyday experience of joint stiffness and pain means that the body cannot be ignored or made to “dis-appear” (Flurey et al., 2014; S. Williams, 2003). Carel (2007) describes grieving for the changing and unpredictable body “appropriated” by RA; “the biological body behaves oddly; it exhibits strange symptoms and becomes unpredictable. The transparent silent function of the biological body is gone” (p. 99). Many of the women within this research shared their struggles of negotiating their “different” bodies, and recalled their efforts, to develop new and alternate methods for performing the “normal” routines of everyday life. Adaptations informed by both physical and emotional considerations were developed by the women in an effort to recreate meaningful interactions and engagements with everyday life (S. Williams, 2000). These practices reflect Coventry et al.’s (2014) concept of a “bodily consciousness,” a way of knowing and being that is able to respond to and priorities “the embodied and emotional work invested in living with illness” (p. 109).

Negotiating Normal

In recent years, the language of “normal” and “normalcy” within disability discourses has been rejected, replaced by the language of ability and capacity (Goodley, 2012). Yet, within the women’s stories of living with RA, one of the key themes arising was their desire to “be” or “remain normal.” Discussions of the “normal” have a long history in the literature on chronic conditions. In general terms, “normal” describes a life with some certainty and predictability, where pain and disability do not override participation in the activities of everyday life (Wiener, 1975, p. 98). For the women in this research, the desire to be “normal” was related to a time and space before diagnosis, before RA. Wiener’s (1975) interactionist research from the mid-1970s identifies the “normal” as part of people’s experiences of RA. In this early

research, Wiener described everyday life for people living with RA as “a nightmare race . . . a constant competition” between two competing domains: the physiological impacts of RA and the activities needing to be performed as part of “normal” everyday life. Uncertainty was generated from not knowing which domain would dominate and in what ways (Wiener, 1975). Two decades later, Whitley, Beck, and Rutkowski (1999, p. 81) draw attention to the link between the “normal” and the “certain.” The “normal” was a space that could be controlled, that was certain, stable, and predictable while allowing for positive spontaneity (Whitley et al., 1999). For many of the women in this research, the “normal” was a space in which the everyday routines, tasks, activities, and interactions with others could occur with minimal interruption from the impacts of RA. Minimal interruption encompassed the absence of or reduction in pain and disability or the capacity to “cover-up” or “keep out” the impacts of RA (Wiener, 1975, p. 98), a description that resonates with Schulman-Green et al.’s (2012, p. 140) concept of the “new normal.”

Adapting to Adaptations?

RA as a disruption “forced” the women to consider adjustment, including what type of adaptation might be made and the implications, personal and social, of any such changes. Since the early 1990s, research focusing on the lived experience of chronic conditions, such as RA, have produced stage models of adaptation (Neill, 2002; Walker, Jackson, & Littlejohn, 2004). These frameworks share a common focus on sequential stages of acceptance, adjustment, and normalcy (Neill, 2002). While such frameworks can be useful in providing a trajectory “mud map” Schulman-Green et al. (2012) point to the focus on the physical and practical to the neglect of the subjective in these models of adaptation. Other approaches can “overemphasise the cheerful, existentially transformative” elements of adaptation, minimizing the “mundane and ordinary features such as pain, mobility impairment, anxiety or dependency” (Thorne & Paterson, 1998, p. 176). The women’s accounts provide differing views and experiences of adaptation, accounts which speak to the “messiness” of living with and “adapting to” RA (Schulman-Green et al., 2012). Physical, social, and emotional adaptations were made within the many spaces the women occupied and involved the embodied negotiation of the structural and relational dimensions of everyday life (Moss, 1997).

It is clear from the women’s accounts that there was no one view of adaptation or one adaptive solution that could be used across all contexts. For some women, assistive aids and other adaptations facilitated their participation in the everyday activities integral to the performance of “being normal.” For these women, achieving “normal” included a readjusted understanding of particular roles and activities, and a reconstructed self which embraced adaptations (Sanderson et al., 2011). Adaptation was not a presumed practice. As some of

the women reported, not all adaptations were considered to be either feasible or desirable. Adaptations could be costly; potential loss of independence increased feelings of being handicapped [*sic*] and further alienation from self were identified as potential barriers and/or deterrents. Adaptations could also be experienced as detrimental to self-concept, a reminder of the “dysfunctioning” or “deviant” body (Dubouloz et al., 2004; Lempp et al., 2006). The ability to choose and to control is paramount in any decision relating to adaptation (Lindsay, MacGregor, & Fry, 2014). For some women, bearing the physical pain associated with a particular activity was preferable to RA imposing constraints and forcing adaptations. For these women, choosing to minimize or ignore the impact of RA can be described as a form of passive coping (Whitley et al., 1999). Rather than a negative response, Whitley et al. (1999) identify the utility of passive coping: a means by which people can continue to engage with an activity despite the associated disabilities. According to Whitley et al., passive coping is actually an adaptive mechanism, providing another means for people with chronic conditions to “maintain a degree of normalcy” (p. 91).

Without ignoring the physical difficulties and emotional struggles which can accompany processes of adaptation, Carel (2007) highlights the potential for empowerment and a renewed sense of autonomy: “Being able to improvise and create new ways of compensating for a lost capacity demonstrates the plasticity of behaviour and the human capacity to adjust to change” (p. 104). For one woman, being “realistic” about her physical capacity allowed her to “lower expectations” and as a result, decrease the emotional fallout associated with not being able to achieve set goals. Adaptation in this sense can facilitate what Lindsay et al. (2014) describe as “a sense of existential power, a power to care for the self” (p. 238).

The Body

Whether feeling removed or separate from her body or consumed by it, each of the women in this research described the centrality of the body within their everyday lives (Ahistrand et al., 2012; Dubouloz et al., 2004; Plach et al., 2004). In RA, the body is the site of pain and disability—it is both object and subject, a biological body and a lived body (Peuravaara, 2013), and it can be experienced as both distant and immediate (Carel, 2007). Everyday activities from house work to shopping were now disrupted by the inconvenience of “the noncompliant body” (Plach et al., 2004, p. 148). Flares also drew attention to the body with the pain experienced as “a form of ‘bodily alienation’ or ‘betrayal’” (S. Williams, 2000, p. 43). For some of the women, the need for adaptations in their everyday lives had led to a new focus on the body, as though recognizing its presence for the first time (Plach et al., 2004). Kelly and Field (1996) identify this awakening of the embodied self as occurring within the context of the noncompliant body, when “the individual becomes acutely aware of

the discrepancy between body and self” (p. 249). Even in times relatively free from pain, the prevention strategies and “body awareness” regimes required a continued focus on the body (Ahistrand et al., 2012). It is clear that within the context of RA the taken for granted status of the body, its previous role as a silently functioning entity (Carel, 2007, p. 99) had shifted to a new focus on the “bodily states not usually brought into consciousness” (S. Williams, 2000, p. 43).

The female body with RA is an important feature of feminist contributions to disability studies (Crow, 1996; Moss, 1997; Wendell, 1996). Research has suggested that the dominant presence of body in women’s understandings and experiences of chronic conditions such as RA is related to their domestic roles, and the positioning of household tasks and activities in their everyday lives (Moss, 1997). In terms of narrative reconstruction, the lived experience of RA had not only interrupted the individual woman but also the woman as mother, wife/partner. The capacity to perform these ascribed roles was important to how the women understood themselves and their position in society more broadly (Moss, 1997). Harrison (2003) highlights the issue of gender in her study with young women who have RA: “As a disease that disproportionately affects women, RA bears on a number of sex-related issues, including reproductive physiology, childbearing and childrearing, social behaviour, and quality of life” (p. 846). However, as some of the women describe, such roles are flexible and can be redefined and reshaped. Drawing on family for support and reorganizing household responsibilities and resources can facilitate the achievement of activities while confirming meaningful constructions of self (Prodinger, Shaw, Stamm, & Laliberte Rudman, 2014). These negotiations resonate with Moss’ (1997) research which focused on the complex negotiations undertaken by older women with RA as they engaged with the household environment, the domestic structures, and the broader social relations within their everyday lives. Moss identifies the active role assumed by these women, demonstrating how they negotiate “space in their home environments, both physically and socially, via continually (re)assessing, (re)shaping, and (re)structuring those negotiated spaces” (pp. 23-24).

Strengths and Limitations

As with all research, there are areas for development as well as directions for future inquiry. Similar to other studies which draw participants from a “clinically captive” population, it is likely that women not accessing health services may have different understandings and experiences of RA. It is also recognized that participant numbers were low and from a geographically limited area. While qualitative research is not number driven, a larger number of participants would have provided further a more in-depth account of the topic. Many of the findings in this research resonate with and confirm the results of other qualitative studies of women’s experiences of

RA. The strength of this research, while providing confirmation for previous studies, is the commentary provided by the women on the “emotional fallout” of RA. This issue is not well covered in the research literature with the focus tending to be on the adaptations people make and the processes undertaken. As is identified in the literature (Carel, 2007; Schulman-Green et al., 2012), there remains a lack of research engaging with the emotional and subjective experiences of people with chronic conditions such as RA. Further research utilizing various qualitative methods (in-depth interviews, narrative journals, focus groups) could document the experience of women with RA, across a period of time and contexts (work, study, “stay-at-home mothers”). The information gathered would contribute to the descriptive data on RA as a lived experience. The focus on identifying the ways in which women engage with and negotiate RA as an emotional-social-physical experience across time and within a diversity of places is particularly important given the current reorienting of Western health and welfare systems. As governments seek to reduce income support costs (disability pensions/allowances) and look to the public and private sectors for employment opportunities for people with disabilities, it is critical that any such policy and practice is based on grounded evidence.

Conclusion

Bury's (1982) depiction of RA as a biographical disruption provides a useful framing for understanding the lived experiences of eight women whose accounts of living with RA have been presented in this research. The disruption to their roles as mothers and wives/partners, the new focus on the body and the tensions relating to adaptation facilitated a re-authoring of the self. A significant feature of the disruptions engendered through RA was the emphasis the women gave to achieving “normalcy” within their everyday lives. At times, when the pain was minimal, living as “normal” was easier it was possible, even momentarily, to forget that RA was part of their lives. During flares, “being normal” was difficult and at times impossible. The challenges associated with flare ups were particularly difficult to negotiate, bringing to the fore questions of personal identity and expectations. Engagement with adaptations, such as the use of assistive aids, was contentious and could be understood as empowering or disabling. Whatever the decision made, what was important for each of the women was “maintaining a sense of value and meaning in life, in spite of symptoms and their effects” (Bury, 1991, p. 461).

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