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The Extended Self: Illness Experiences of Older Married Arthritis Sufferers

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SEDAP Research Paper No. 39

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THE EXTENDED SELF: ILLNESS EXPERIENCES OF OLDER MARRIED ARTHRITIS SUFFERERS

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Abstract

A large epidemiological survey evaluating the extent of arthritis in the population aged 55+ uncovered a discrepancy between medically assessed need for and patient willingness to consider treatment involving total joint arthroplasty. In an attempt to understand this discrepancy, we conducted a qualitative study to assess patients' experiences of the disease. This paper is focused on how the quality of the marital relationship influences the everyday functioning of arthritis sufferers. Our results suggest that in addition to the *individual's* functional capacity, the *couple's* relational and functional behaviours influence the meaning of the disease and an individual's health care decision-making.

Introduction

A recent epidemiological survey of the community dwelling population aged 55 and over living in two regions of Ontario, Canada uncovered a substantial discrepancy between medically-assessed need for joint arthroplasty for hip and knee arthritis and patient willingness to consider this intervention. Study investigators concluded that among individuals with severe disease, there is under-use of arthroplasty among men and women[1], and that the provision of extensive information about its availability and benefits did not necessarily improve patient demand or interest (Hawker et al., 2000; 2001).

From the perspective of medical specialists, this discrepancy is problematic, given that joint arthroplasty has been found to be cost-effective and efficacious in the treatment of pain and functional disability for advanced arthritis of the hip and knee (Hawker, et al., 1998; Chang et al., 1996; Laing, et al., 1986). The finding that patients under-utilize this treatment option may reflect both physicians' perspectives on the appropriateness of this treatment and their referral patterns, and patients' perspectives on and responses to the disease, including successful (or adequate) coping strategies. This paper is focused on the latter of these potential explanations.

An understanding of health care decision-making by patients with a chronic, non-terminal condition such as arthritis requires investigations of the *illness* experience—that is, the subjective experience and meaning attached to physical conditions by patients (Susser, 1973). A focus on the patient's perspective is particularly important for understanding the management of arthritis. Its growing prevalence in an aging population suggests that it will increasingly be presented in patient encounters with physicians. For example, arthritis is one of the most common chronic conditions in the population aged 65+ (Verbrugge et al., 1991**.** It is estimated that 85% of

Canadians will be affected by osteoarthritis by age 70 (Health Canada, 2000). Arthritis is a leading cause of permanent incapacity, and an important determinant of disability and institutionalization in elderly populations, particularly for elderly women living alone (Badley, et al., 1992; Peyron and Altman, 1992).

Yet, the nature of arthritis determines that the afflicted individual usually *ages with the disease*. This long-term experience takes place within a changing social context so that the symptoms and effects of the disease may be re-interpreted as the context changes. And, the illness may take on different meanings for the individual who has increasing experience managing its symptoms. Only by understanding a patient's unique historical account of their disease can medical practitioners understand the discrepancy we describe above.

We undertook a study to examine how individuals experience arthritis in their everyday social environments, and how they cope with symptoms—including chronic and episodic pain, and functional limitations. In another paper, we present a multi-level model of the individual, social-interactional and social-structural features of patients' lives in which the experience of arthritis and responses to it are contextualized (Ballantyne et al., 2001). The social-interactional context includes the proximal and every-day interaction of the marital couple or other co-habitants, as well as the broader social network that includes informal and formal ties that serve as social resources for the individual. For our current purposes, we limit our analysis to married respondents. Specifically, we describe the relationship between the quality of the marital relationship and an individual's perceptions and experience of arthritis, and their views of total joint arthroplasty as a treatment option.

The focus on the married couple is important. The marital relationship is important because it generally includes a long-term intimate socio-emotional relationship as well as established functional roles that are important for the identities of each member of the dyad. Marital status has long been used as a key measure of social support in health and social surveys. An abundant literature indicates that marriage, in general, is health enhancing. At any given age, married people have lower morbidity and mortality rates than unmarried people (Koskenvuo et al., 1986; Morgan, 1980; Trovato and Lauris, 1989). Explanations for the relationship between marital status and health include higher levels of material resources, lower levels of stress, and the quality and intimacy of social support among married individuals that may not be available to individuals who are not married (Wyke and Ford, 1992).

Yet, marriage can also involve costs and risks, especially in the face of adversity such as chronic, debilitating and terminal illness, particularly when the caregiver is elderly and in a compromised state of health (Rose and Bruce, 1995). Illness of one member of the couple may challenge the everyday functioning of the spousal unit, and the couple's response to the challenge will determine how the individual responds to illness. Marital status also affects identity (Askham, 1995) so that the quality of a marital relationship can mediate self-perceptions and the psychological capacity of an individual to define and respond to chronic disease.

Methods

The methods and analysis of data are described more fully elsewhere (Ballantyne, et al. 2001). Here, we analyze in-depth qualitative interviews with 16 married individuals with severe disease. The interviews were guided by a semi-structured interview schedule. The schedule allowed the interviewer to ask respondents about past and present experiences and future expectations of their disease and to gain insight into a respondent's perspective on health care decision-making for arthritis, and allowed *respondents* to move the interview in directions that were relevant to their own experiences. The interviews were in pursuit of the general question "in the context of their everyday lives, how do aging individuals' perceptions of and experiences with arthritis influence their management of the disease on a day-to-day basis?"

Sampling and Sample Characteristics. Responses from married individuals are based on a sub-sample of the original qualitative study (see Ballantyne et al., 2001). The original study included 29 individuals aged 55 and over who have arthritis, who were selected for the study based on clear inclusion criteria: following a three-stage assessment in the larger survey, they reported and were objectively assessed as having *severe arthritis*; they were medically assessed as appropriate candidates for total joint arthroplasty (tjr); and they rejected the tjr option after being given detailed information about the risks and benefits (for details see Hawker, et al., 2000; 2001). Further selection was based on respondents' willingness to participate in the qualitative study, which represented a fourth contact with study investigators. The sample then, is not random, and findings may not be representative of all individuals with severe arthritis.

Seventeen of twenty-nine individuals who agreed to participate in the qualitative study were married at the time of their interview. One interview was excluded because of difficulties in transcription. The married respondents include 9 women and 7 men; primarily between the ages of 60 and 70, and representing two distinct geographic regions (a rural/small town area and a metropolitan area). These sample characteristics are outlined in Table 1.

Table 1 About Here

Analysis. All interviews were tape recorded and transcribed verbatim. Transcripts were subjected to inductive content analysis (Berg, 1995; Holstein and Gubrium, 1994; Strauss and

Corbin, 1994; Glaser and Strauss, 1967). This involves multiple readings of the text of the transcripts. At first reading, central themes and major general issues were identified. Subsequent readings resulted in an open-coding scheme. This phase is complete when the codes have become "saturated", and involves repetitious reading of the text until all data is coded. Analysis of the transcripts, following this pattern of iterative review of themes, codes and sub-codes, allows the analysis to move from description to explanation, from the concrete to the more abstract, following the grounded theory methodology (Glaser and Strauss, 1967). Ethnograph software for the management of text-based data was employed for open data coding (Qualis Research, 1998).

Results

Qualitative data codes that were the exclusive domain of married respondents were extracted from the codebook. Four specific codes were unique to married respondents: division of household labour, dependence on spouse, support from a spouse, and conflict with spouse. The first two describe *activities.* "Division of labour" describes a respondent's self-assessed responsibilities in terms of the maintenance of a household and household members. "Dependence on spouse", a marker of functional limitation of the respondent, refers to situations where a respondent is unable to perform a specific activity or function without the assistance of their spouse. The second two codes describe *characteristics of the interaction or relationship* between the respondent and their spouse. "Spouse support" describes the respondent's acknowledgement of *positive* interaction and assistance from the spouse for carrying out specific activities or functions. "Conflict with spouse" refers to a respondent's report of overt or latent *negative* interactions with the spouse.

It is important to note that these codes are not mutually exclusive, and their co-occurrence in the data reveals the richness of text-based analysis. The complexity of marital interaction may be expressed, for example, in a case where a respondent describes dependence on their spouse for an activity such as assisted walking outside the house, and conflict with the spouse over this arrangement. Or, one individual may describe being dependent on a spouse for the completion of some activity (implying inability to perform it independently), while another will describe receiving support from a spouse in carrying out an activity that would otherwise be very difficult to perform independently. The difference here is subtle, with these distinctions marking the degeneration of function that some experienced, as well as the strategy for coping with that degeneration, based on co-operative social interaction with the spouse. It may be the case that the functional ability of two individuals is similar, but the *perception* of their function is moderated by how the spouse serves to assist the respondent in managing a physical limitation.

In the text that follows, we describe these four coded categories more fully. Then, on the basis of our analysis of respondents' activities and interactions with the spouse, we define three distinct types of marital relationships. The relationship between these marital types and respondents' everyday experiences of arthritis, and their perceptions of joint replacement surgery as treatment, are examined.

Sharing labour: the d*ivision of labour as a social context for married individuals with arthritis.* Of 16 married respondents, 14 discussed a division of labour in the household as a context in which they had to negotiate activity levels because of physical limitations related to arthritis and other co-morbidities (7 women and 7 men; 12/13 county residents and 2/3 city residents). These negotiations were with themselves, with their spouses, or with others such as friends or formal service providers. Several codes occurred simultaneous to, or as an over-lap to the division-of-labour code, providing insight into how household activities were negotiated and managed by the individual with severe-stage arthritis. These included details of the physical condition of the respondent (such as medical complications or co-morbidities, physical restrictions, functional decline, need for the use of props such as a wheelchair), the individual's psychological response to the disease state (such as resolve and a commitment to "keep going", or frustration), the social resources available (self sufficiency or reliance on self, spouse support or conflict, dependence on the spouse, social network and social exchange), responsibilities for others (caregiving), and strategies for coping with activity demands related to household labour (using restraint such as avoiding activities, using an activity control cycle, for example, will exert oneself over housework one day and refrain from exertion of any kind, the next).

Gender differences related to the management and division of household labour among individuals with arthritis were evident. Among married women respondents, 4 described a separate division of labour between the husband and wife, and 3 described a co-operative or shared division of labour. Among those describing separate roles, simultaneous coded responses included self sufficiency and resolve (referring to the individual's commitment to their role in household activities), use of restraint in carrying out activities, recognition/acceptance of functional decline and physical restrictions that limited activities related to household roles, and spouse support[2]. Among those describing co-operative or synchronous roles, simultaneous codes included spouse support and dependence-on-the-spouse, and social exchange in the context of work shared with the spouse.

Among the married men, 5 described a co-operative division of labour in the household (shared roles related to household work), 1 was physically dependent on the spouse for most activities, and 1 described a separate, gendered division of labour. This latter individual described reliance on his adult children and a broader network of friends to assist him in maintaining *his* responsibility for work outside the home (while his wife retained responsibility for work inside the house—cooking, cleaning, decorating and maintenance, etc), and he stated he had, and was able to purchase formal assistance, in order to continue *his* "usual responsibilities".

Gender differences in respondents' discussions of the division of household labour were revealed in another way as well. While only 2 of 16 respondents described care-giving responsibilities as an aspect of their household work, both respondents were women (Another male respondent discussed *his wife's* ongoing responsibility for continuous care to him). Despite their own physical health problems and functional limitations, the two women discussed their commitment to care-giving provided to adult children (one woman discussed past caregiving of an adult son with mental illness, and another woman discussed her strategies to minimize the burden of care-giving to her adult son who she viewed as having significant support needs related to his poor health, broken marriage, and parenting responsibilities). The husband of this latter woman was also highly dependent on her because of his poor health. She included the care of her husband as part of her everyday household labour, and she acknowledged that the burden of care was difficult because of her own state of health. Importantly, she demonstrated how she did successfully find some relief:

R: …I, huh, picked up my husband a few times already too, but I'm getting smart. That, too, I..I've learned how to make him know--I've got to learn HIM to do it. Because if I'm not here....

I: You can't do everything for him.

R: So, I says, "Come on, do it." So the shower with--he's accomplishing more and more all the time. And he's really getting particular now, he wants this kind of clothes and, ah, gee, you know, you're really getting back to normal, you know. But he did...he does his toes, and the only thing I do is maybe the back to make sure it's dry, you know, and ah, he dresses himself now. Used to be I had to help him all the time.

Differences in the division of household labour by regions (small town/rural and urban) are notable. Only 2 of 3 married city dwellers discussed the division of labour as an aspect of life they had to negotiate because of their arthritis condition, while 12 of 13 county dwellers discussed the division of labour. The city dwellers are both men, living with their wives in high-rise apartment buildings. For these two couples, “outside work”, usually described as the domain of men in the county sample, was not an issue at all. Among the county residents who discussed the division of labour between themselves and their spouse, 12 lived in houses; only one lived in a retirement residence, and did not have responsibility for “outside” work. This difference will explain, in part, the stronger presence of a gendered division of labour among the county residents.

With respect to respondents’ discussion of the negotiation of the household division of labour, it appears that rather than the disease curtailing (household maintenance) activities, respondents’ attachment to a gendered division of labour may assist arthritis sufferers in keeping the negative aspects of the “*disease”* label at bay. The maintenance of normal, valued social and household activities may be identity-confirming—the maintenance of these valued roles no doubt assists the individual to feel continuity with their past self. While the *performance* of activities may be modified because of physical status, respondents revealed a reluctance to give up valued or usual social roles; as if this implied *giving in* to the disease.

Dependence on Spouse and Conflict with Spouse. Of 16 married respondents, 6 described being dependent on their spouse for assistance with daily activities (3 women and 3 men; 4 from the county sample and 2 from the city sample). "Dependence on the spouse" indicated that an activity couldn't be performed without the spouse's assistance, and so referred to activities related to specific tasks, as well as to an overall state of dependence and loss of self. (In this data set, two individuals had physical limitations so extensive that they were totally dependent on their spouses, and described themselves in this way.) Dependence on the spouse was related to the presence of physical restrictions and functional limitations related to (an) illness(es).

Dependence for assistance with a specific activity could be offset when reciprocity was retained by a fair or usual balance of exchange in tasks and interactions in general. In discussions related to dependence on a spouse (in general, and related to the specific activities), the simultaneous experience of conflict with the spouse was indicated by several women. These two themes are discussed below.

Overlapping codes for those who describe some level of dependence reveal differences between how these women and men feel about their dependence. For women, codes that overlapped with "dependence on spouse" included having physical restrictions, division of labour (so their dependence is related to difficulties in the performance of some self-defined household task), feeling supported by their spouse over their dependence needs, desire for formal services and scarcity of money to purchase such services, and conflict--for example, over negotiating to get assistance with specific tasks from their husbands). One woman who reported conflict over the fact of her dependence and the manner in which her husband provided assistance, at a different point in the interview also remarked on how supportive her husband had been--so being in conflict over interacting with a spouse occurred in the same context where the spouse's support was acknowledged. Two women who described being in conflict with their spouse stated it was over the fact that their husbands didn't want to talk about, or hear them "complain" about their health problems. Another's husband had had a stroke and was no longer able to share a companionable relationship (where the two could share in conversation) such as they had had in the past. Another woman—highly physically dependent for daily care from her husband, experienced conflict with him around a myriad of issues: her physical care such as mobility, toileting, eating of meals, her interaction with others (family, health care aid), and her relationship with him.

In contrast, none of the men who described situations of dependence on their spouse described conflict over the arrangements. Three males reported dependence based on physical restrictions related to having arthritis and other health conditions, their need for exercise-therapy and the completion of household activities that they defined themselves as responsible for. Simultaneous codes for these men included acknowledgement of the support provided by the spouse, their psychological response of resignation to their arthritis condition, and their resolve to continue to attempt to cope as best they could, and even their feelings of being self sufficient *(as a couple)* in meeting their needs. So in general, dependence appeared less problematic for men than for women.

In terms of regional differences in response to being physically dependent, one county resident described her reliance on her spouse because she was unable to climb the stairs in her house to fetch stores, etc. Two other (female) county residents described reliance on the spouse for driving. The two city dwellers who described being dependent were not constrained by the location or type of residence, but rather by their poor health--including significant co-morbidities, in addition to severe arthritis.

Suppport from Spouse. Of 16 married respondents, 13 acknowledged that their ability to cope was due, at least in part, to the support provided by their spouse (6 women and 7 men; 10 county residents and 3 city dwellers). "Spouse support" describes the respondent's acknowledgement of *positive* interaction and assistance from the spouse for carrying out specific activities or functions. This category is subtly different than "dependence on spouse" because the respondent describes the *ability to perform activities and function because of* support received, rather than *an inability to perform an activity* or function.

Discussions illustrating support are related to several topics, including fulfilling one's responsibilities related to the division of labour; managing physical restrictions and medical complications related to co-morbidities, maintaining a workable psychological orientation to illness (maintaining resolve, managing uncertainty, maintaining a sense of self sufficiency), a moral philosophy of responsibility to "keep going", having ongoing social interaction with friends and family, and availability of the spouse as confidante as well as the provider of instrumental support.

Support from a spouse was not always viewed as unproblematic, and as we note in the discussion of conflict, above, gender is not irrelevant here. For example, we mentioned previously, the case where a woman who is functionally dependent on her spouse for most tasks acknowledged both supportive (positive) interaction with him, but also serious conflict in some interactions. Additionally, one female county resident, who was relatively young—aged 63 at the time of the interview, indicated that while she has a co-operative relationship with her spouse and her needs were being met at the time, her future is uncertain. She states:

R: "well, if..if, ah, well right now I'm managing; I'm doing alright, like I mean I have him, but…if I was left alone that might be a different situation. That's not a nice way to talk, but I mean you have to be realistic about things. Like he's four years older than I am. But then again, he helps. He says (whispers) 'I'm gonna outlive you' (chuckles)."

Finally, it is notable that 10 of the 13 respondents who discuss supportive exchanges with their spouse as an aspect of living with severe arthritis are county residents. Most of these individuals continue to live in houses, maintain yards and gardens and vehicles. Supportive interaction with the spouse is one of the ways in which independent living (and for some, independent, gendered roles) is maintained.

Our discussion of these four codes—division of labour, dependence on spouse, support from spouse, and conflict with spouse--highlight the ways in which respondents experience arthritis in the context of their marriages. "Division of labour" and "dependence on spouse" describe respondents' negotiations over the completion of *activities*. These activities relate primarily to self-defined social roles in the household division of labour, and for some women, in caregiving work[3]. "Spouse support" and "conflict with spouse" describe respondents' perceptions of their everyday *interactions* with their spouses (as positive, ie: supportive; or as problematic, ie: conflict)—that is, the *relational* aspects of coping with arthritis, within the context of marriage.

On the basis of these codes, we apply three concepts to describe variations in the quality and function of respondents' marital relationships. These include synchronous relationships, independence relationships, and dependence relationships. The relationship between these marital types and respondents' everyday experiences of arthritis, and their perceptions of joint replacement surgery are summarized below.

The synchronous marital relationship. Three of nine women respondents and five of eight male respondents are in marital relationships that we define as “synchronous”. Synchrony, in these cases, includes both the sharing of activities as well as a shared state of mind. In sharing activities, the wife and husband may be attached to specific, and even traditional (gender-divided) roles, but one individual will act to compensate for the other’s functional limitations, they will do this in a supportive manner. This compensatory-sharing will be viewed as unproblematic; as an aspect of the marriage that evolved as the couple aged. The following excerpt illustrates this view of shared activities:

I: Is there some division of labour or do you do most of the stuff, between you and your husband?

R: Ahm, well as far as the housework …is concerned, I do.

I: Everything?

R: …..He does a lot of other things. Like he does, ahm, he does everything outside except my flower garden and I do that. I make--I love my flowers and I just get out and do it. I pay up for it, but I won't give it up. Because I figure it helps.

I: And it's pleasure.

R: That's right. Yeah….

I: Yeah. Can you climb stairs easily?

R: Ah, I can--yes, I can climb them, but I can't, ahm…

I: Go down.

R: Yes I can do it, but I can't do it like three or four times. If I do it three or four times in a day, I pay up--I really pay up for it. So I usually--like I've already been down once today; I will--if I have to go down once more, but I won't, you know…… I can't.

I: Yeah. So who does the laundry?

R: Oh, it's up on my main floor.

I: Oh it's up, okay.

R: And that--I had that, yeah, yeah, yeah.

I: This is taken care of.

R: That's taken care of. So lots of times there's no reason for me to go down there. Ah, the only thing is my freezer and sometimes I ask him to get me stuff out of it.

I: Is it easy or do you need to bargain or is he responsive?

R: Oh yeah, yeah, he's fine, yeah, yeah, yeah. And ah, I have a fruit cellar but now I've got everything out of there except a bit of canned stuff, but ahm, what I'm trying to do is when I go downstairs for one thing, I try to bring everything that I need up at the same time.

Synchrony, as we describe it here, allows (household) role-continuity, and thus serves to preserve the identity of an individual whose physical state of health is compromised. The broader text from the interview above reveals the respondent's longstanding pattern of negotiation with her spouse that continues to the present time. Another respondent's (a male) discussion of his interaction with his spouse illustrates how the couple works to support one another. It is significant here that this man's wife also has functional limitations related to her own physical health status:

I: Well, how do you handle the housework?

R: We do it between the two of us. If we don't do it today it gets done tomorrow or some other day. Don't worry too much about it.

I: Who does the groceries, or how do you do it?

R: Both of us. We go-we go with the Wheel-Trans. We take the Wheel-Trans, (coughs) that way she doesn't have to do much walking and I have this wheelchair anyway.

Another man, with a wife who also has arthritis (the wife has recently had two knee replacements), describes how he acts to compensate for his wife's functional limitations; while at the same time, recognizing his own limitations:

I: So what do you do now? Can you briefly describe for me one day, how does it go? You wake up in the morning and then what do you do? A typical day.

R: Not a whole lot. It's...whatever housework has to be done, try and do that and cook the meals and stuff and...the washing has to be done and do the washing, she doesn't--she hasn't done that for a couple of years, two or three years now. I can go up and down the stairs but it's not the greatest thing in the world to do. And (clears throat) you know, clean the house, vacuum, make the beds and she'd make the beds, she's starting to make the beds lately. But for a while there she wouldn't (unclear).

R: If we go for groceries, like we go for groceries ear--early in the morning is my best time. Like after resting the night, early in the morning is my best time. We'll go for groceries and go around the store and we'll maybe (wife) will sit down and have a coffee somewhere, rest there for a while --and come home and...put the groceries away and I'll lay down for a while and you know, just anything that…

I: Yeah, yeah.

R: Some days I can't do anything. Some days I won't do anything.

Finally, in a conversation about everyday coping, another man expressed a psychological/emotional attachment to his wife, in his everyday battle to "keep going", in both a physical and emotional way:

I: Do you walk?

R: Oh yeah, I walk from here, the garbage chute's away down the other end of the building; I take the walker and I walk around a bit.

I: Okay, yeah….This is good…..

R: Oh yeah, I'm not gonna give up that quick. No way! …..Well especially if …if there've been two people and one dies, the other one gives up altogether. But we got each other (speaking of wife) and that there keeps us going. I think that's what helps a lot really.

It is notable that in the above example, and in other transcripts from interviews with individuals in synchronous marriages, it was typical to see references to "me" or "I" replaced with references to "we" or "us".

Referring specifically to the respondent's assessments of total joint replacement (tjr) as a strategy for coping with their condition, among those that we describe as having synchronous marital relations, 4 indicated that they would be willing to undergo trj in the future (that, contrary to the medical assessments conducted earlier, they viewed trj as premature at the point of our interview, and several defined trj as potentially appropriate or necessary in the future). Four others in "synchronous" relationships were reluctant to consider tjr, even as an eventuality. Reluctance was based on reasoned consideration of past (negative) medical and hospital experience (Ballantyne, 2000) and of complicating health conditions that the individuals themselves viewed as contraindications to surgery (such as overweight). It may also be the case that *the couple* were coping sufficiently well to preclude consideration of an invasive procedure such as joint arthroplasty.

Our discussion of marital synchrony, as reflected in interactions around the completion of activities as well as at the psycho-emotional or relational level, illustrates the notion of the "extended self". The study of the *self* is concerned with the implications of the human capacity to reflect upon one's own physical, social and psychic state. Further, the self-concept is influenced by an individual's evaluation of how others view them, and how they view themselves according to socially defined rules and expectations (Mead, 1956). On the basis of our analysis, we suggest that, for some individuals, an intact sense of self can be maintained in a context of synchronous marital interactions—those that accommodate desired or usual social roles, and those with positive and reinforcing social-emotional relations between the members of the couple. The concept of "the extended self" conveys the idea that an individual may conceptualise functional limitations in the context of their most intimate relationships so that it may not be the *individual's* functional capacity, but the *married couple's* capacity to function interdependently that determines the meaning of the disease and an individual's health care decision-making.

The independent marital relationship. This marital type describes a relationship characterized by separate and distinct social and emotional spaces for the members of the couple. Typically, these arrangements are mutual and functional--the result of habits of interaction established between the couple long ago. In the following example, the discussion is focused on the option of joint surgery:

R: Ahm, but I just don't like the idea of not being up (chuckling), being handicapped for three weeks or four weeks or whatever it is.

I: Well if in that case, is there anybody who could help you, you know, go through this period? Because it's only for a while.

R: Well, my husband might have to. Ahm, he's not a nurturer.

I: It is a type of personality….

R: Yeah, yeah, yes, his mother did everything and he wasn't expected to do anything--well they lived--he was raised on a farm, you see, so that manual work is fine but..... Yeah, he will hel--he helps me if I....I have a girl come in, ahm, every other week to help with house cleaning. She's helping me with the gardening too.

I: So otherwise you do the housework; or do you share things with him?

R: No-o, no (laughs). I clean up after him.

I: Okay. So if you needed some help anyway, would he need a lot of, you know, (unclear)-

R: Oh no. No, no, no, he'd be, no he would help me. Yeah.

I: Okay. Just not his style.

R: No. No, he'd rather not, but ah, no --he won't do it unless I ask him, but if I ask him he'll do it. |

Another respondent indicates a mutual arrangement of separation of roles, between he and his spouse (it is his friends who assist him in maintaining "his side" of the arrangement);

I: And has it been hard for you because you run a house, you and your wife live in this house and run the house; has there been any indication that you won't be able to keep the house up because of your concern or your wife's concern about your health?

R: I don't think so, because she's quite able to do anything that...about the house if I couldn't do any, she could do it herself.

I: Has there been an exchange of roles to any significant degree...

R: No.

I: ...in that sense where she's had to take on more?

R: No, she's always done everything in the house and I do everything outside.

I: And you pretty much keep that up now?

R: Yeah.

I: You just take the time you have to do it, and you have more time to do it now?

R: Well, when we had the snow, big snow storm, a friend of mine, he come up and he said, "Don't you be snow-blowing", so he came up and blow my snow. I got friends who can do that….

However, aging, illness and disability may render long-established patterns of independent roles cumbersome, and even deleterious, for one member of the couple. For example, in the following case, the respondent described long-standing divided marital roles. Her husband's deteriorating health led to his inability to care for the "outside" work, and their decision, eventually, to move into a retirement apartment. She fiercely defends her turf as the homemaker (and now, caregiver to her husband), but has had to confront the collision of their previously separated worlds:

R: And he'd never seen a lot of me. And now….Because he's never seen me. I says, "I've been like this for ten, twenty years, M., you're just not around. Like I'd be laying upstairs or something, you know, laying down and he wouldn't pay, you know, 'oh, the patient's laying down'. But now he sees that it's.....

Another woman describes a significant conflict she is currently facing, relating to housing:

I: You mentioned you were going to--you wanted to sell the house. What will you go for as a next step?

R: I'd love to go home out west, where it's nice and dry.

I: Because of the climate.

R: Um-hm.

I: Can you? …would your family agree with that, your husband?

R: I don't know. I don't think, I don't know about X. He wants to go to a hot country and I won't go, can't stand the heat. No. I love my winters and I couldn't…. I couldn't go somewhere to be not winter (chuckles).

I: But what kind of housing situation would you choose, would that be a house again or?

R: I hate the thought of apartment living. But...every house has some property and it has to be kept up.

I: What would you--have you thought about this? What kind of arrangement you choose next?

R: Not really, because it's just lately after years and years of trying to get him to... say yes to selling the house, ah, he's only agreed. Now I think he's starting to back pedal because he digs his heels in about everything. But, ah, I don't know. If we can't agree we will have to go our separate ways.

This latter case illustrates that the divisions that exist between the respondent and her husband may be insurmountable, *so the marriage itself, may be a serious deterrent to her effective coping with severe arthritis*.

With respect to the joint replacement (surgical) option, among those in “independent relationships”, three of five viewed tjr as a likely eventual outcome; one expressed great reluctance to consider this option, and one did not place much emphasis on the management of arthritis because of his successes at reversing functional decline (through diet, exercise, weight reduction and “a good attitude”) and because of serious co-occurring morbidities. Recall that these views of the severity of the disease (and of the options for treating it) are contrary to medical assessments completed earlier in the study. And, for all respondents we categorized as in an independence-type marital relationship, none offered views on how they would eventually cope with functional loss and increased dependence. Perhaps their coping strategy could be described as avoidance.

The dependence relationship. Two respondents were dependent on their spouses for everyday functioning. In these cases, the capacity for reciprocity between the couple is limited. Dependence states were described in both positive and negative terms. For example, the following excerpt is from a male county resident who is highly dependent on his wife but who describes having a very positive relationship with her:

R: Yeah. Both my wife and I have retired, and we have a....fixed income. It's awfully hard to retire, I'll tell you….(laughs) Boy, it's like going from black to white, you know, or white to black, sort of thing. And it takes months upon months to...put in gear…you know, routine and everything.

I: How do you handle that?

R: Oh, well, like everything else, sorta you're not going to make anything better by…
...by struggling against it, you sorta got to go along with things; and I'm lucky that, ah, … that, ah, both my wife and I, we cope pretty well, luckily I got the wife that I have.

I: Oh yes. She must be helpful.

R: Oh, yes, yes she is. Yes, she looks after me like a baby, I guess (laughter). I don't go out any more when there's snow around or ice because I lost all my self-confidence since this accident, you know.

Since retirement, this man has come to live a very circumscribed existence. With his wife accompanying him on all outings, as well as caring for him in the home, he remains optimistic, and frequently expressed gratitude for his wife. This individual is unusual with respect to his optimism in view of his current (dependent) status. In most cases included in this study, the maintenance of independence, or at least the capacity for reciprocity in interactions was a central goal for everyday life (and resistance to the joint replacement option was often based on concern about even temporary dependence). In the current case, where the respondent's dependence on the spouse is described as non-problematic, the interpretation of the marital relationship as being primarily positive may reflect a reality based on a re-evaluation of self and identity-expectations, or it may reflect a process of interpretation described as marital aggrandizement (O'Rourke et al., 1998); that is, the respondent's suppression or negation of memories or beliefs that contradict a desired perception of the relationship.

Contrary to the above case, a more ambivalent view of dependence on the marital partner is evident in the following excerpt from a woman with declining health and increasing dependence on her husband:

R: I got everything wrong with me and I feel so useless….you know, you can't help it but…feel useless when you've worked all your life and done things for yourself, and then you find that you just can't do anything. You know, I mean, it's really embarrassing when you have to—he has to help me to walk, he has to help me up the stairs. If I'm going, ah, I'll walk—I'll go the wrong way. You know, it's so, oh, it's so bad. And people don't realize…" "And especially for someone who was always used to doing for myself—I've been working since I was 12; and to have to depend on somebody so

> totally, it’s really horrible. I’d like to be able to get up and kick my heels up and you know, just do all the things other people do.” .

The two individuals that are functionally dependent share the view that trj is not an option at all. Their decisions are based on their own views of their health problems, of medical complications that they view as contraindications to surgery, previous and numerous hospital experiences and an unwillingness to subject themselves to more hospital care, and uncertainty about the outcomes of tjr.

Discussion

This paper is focused on the marital relationship as potentially influencing how an individual perceives and experiences the disease of arthritis. The marital relationship is important because it generally includes a long-term intimate socio-emotional relationship as well as established functional roles that are important for the identities of each member of the dyad. Illness of one member of the couple may challenge the everyday functioning of the spousal unit, and the couple’s response to the challenge will determine how the individual responds to illness.

We identify three marital types: synchronous, independence and dependence relationships. Synchronous relationships involve both the sharing of activities as well as a shared state of mind. In sharing activities, the wife and husband may be attached to specific, and even traditional (gendered) roles, but one individual will act to compensate for the other’s functional limitations, and they will do this in a supportive manner. This compensatory-sharing will be viewed as unproblematic; as an aspect of the marriage that evolved with time. Synchrony, as we describe it here, allows (social) role-continuity, and thus serves to preserve the identity of an individual whose physical state of health is compromised.

Our discussion of marital synchrony, as reflected in interactions around the completion of activities as well as at the psycho-emotional or relational level, illustrates the notion of the "extended self". The study of the *self* is concerned with the implications of the human capacity to reflect upon one's own physical, social and psychic state, and the self concept is influenced by how an individual views themselves according to socially defined rules and expectations. We suggest that, for some individuals, an intact sense of self can be maintained in a context of synchronous marital interactions—those that accommodate desired or usual social roles, and those with positive and reinforcing social-emotional relations between the members of the couple. The concept of "the extended self" then, conveys the idea that an individual may conceptualise functional limitations in the context of their most intimate relationships so that it may not be the *individual's* functional capacity, but the *married couple's* capacity to function interdependently that determines an individual's sense of self, the meaning of the disease and an individual's health care decision-making. This is illustrated in our interviews where individuals refer to "we" and "us" when discussing their strategies for coping with severe arthritis.

The independence relationship is characterized by separate and distinct social and emotional spaces for the members of the couple. Typically, these arrangements are mutual and functional--the result of habits of interaction established between the couple long ago. These arrangements, however, may become problematic and even damaging for one or both members of the couple, as they encounter illness and disability. While synchronous relationships accommodate the physical state of decline and make it manageable so that individuals delay or avoid strategies such as tjr, independence relationships are potentially problematic, at least from the perspective of continued and separate functioning. Synchrony or co-operation is not typically expressed in respondents' discussions of marital relations, and although the spouse may be accommodating, some women respondents indicated that assistance from the spouse is not easily acquired; some described having to coerce or trick spouses into assistance. In one case, insurmountable barriers to continued co-existence were indicated, suggesting that the marriage itself may be a serious deterrent to effective coping with severe arthritis.

Finally, dependence relationships, characterized by a limited capacity for reciprocity between the members of the couple due to the functional status of one, were described in both positive and negative terms. One man had ceased functioning with any independence, and acquiesced to dependence on the spouse. Recognizing the imbalance in his relationship, he nonetheless described it in very positive terms, and himself as “lucky”. In the other case, the woman lamented her total loss of function and dependence on her spouse. Her frequent reference to her past self, and previous roles, were notable. To highlight the contradictions between what we described earlier as the “extended self” sustained in the synchronous marital relationship, these two cases better illustrate an “expended self”—the near total loss of function and the self as an autonomous being. It is notable that these two individuals were not dependent solely or even primarily because of arthritis, rather serious co-occurring morbidities led to their functional and emotional declines.

There are three important implications of this study. First, it should not be assumed that marriages are supportive; and it should be assumed that among aging individuals, the capacity for support within the marriage may be diminished with time. Second, individuals within marriages can identify specific needs—the maintenance of homes, gardens, the need for assistance to maintain normal social interactions, the need for assistance in preparing meals, and with personal care activities of daily living, etc. Third, where these needs cannot be met within the marital home (either because of the inability or unwillingness of the spouse to assist; or because of limited economic resources), alternative means of access ought to be pursued, in the name of health care.

Endnotes

[1] The study concluded there is under-use of arthroplasty for severe arthritis in both sexes, but the degree of under-use is more than three times as great in women as in men (Hawker et al., 2000).

[2] An example of spouse support for the respondent's independent household role included a situation where the husband would fetch groceries for storage so that the wife could prepare meals.

[3] The paper is based on discussions of the marital relationship. Text related to how respondents with severe arthritis negotiate within their broader social network is excluded from this paper, but is also less common in the interviews. This is because of the age and life stage of these respondents (most are retired), and because for many, their advanced disease status means their everyday lives are centered primarily around activities (and non-activity) in the home, and interaction with their spouse.

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Table 1:

Summary Characteristics of Married Respondents with Severe Arthritis

Characteristics	Total	County Sample	City Sample
Age **<60**	1	1	0
60-70	12	11	1
70-80	3	1	2
>80	0	0	0
Sex			
Female	9	7	2
Male	7	6	1
N	16	13	3

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