Independence and Dependence for Older Adults with Osteoarthritis or Osteoporosis*

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RÉSUMÉ
Au moyen de méthodes qualitatives, cette étude explore la perception de l'indépendance et de la dépendance qu'ont les ainé(e)s atteints de déficience chronique musculosquelettique. On a effectué 27 entrevues en profondeur auprès d'ainés souffrant d'arthrite et/ou d'ostéoporose et vivant dans la communauté métropolitaine de Toronto. Les personnes interviewées partageaient dans l'ensemble une perception semblable de l'indépendance et de la dépendance mais leur vision d'eux-mêmes relativement à l'indépendance été liée au type de difficulté éprouvé, aux capacités d'adaptation, aux appareils et accessoires fonctionnels et à la nature des relations d'aide. Nous avons divisé les personnes interrogées en trois catégories selon le type de difficulté éprouvé (mobilité au sein de la communauté, activités domestiques, soins personnels) pour illustrer la façon dont elles définissent leur indépendance en regard des trois autres facteurs.

ABSTRACT
This study uses qualitative methods to explore subjective perceptions of independence and dependence for older adults with chronic musculoskeletal conditions. Twenty-seven in-depth interviews were conducted with community-dwelling older adults with osteoarthritis and/or osteoporosis in the

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greater Metropolitan Toronto area. Respondents shared similar overall perceptions of independence and dependence, but self-definitions as independent were related to domains of difficulty, coping skills used, assistive devices, and nature of the helping relationship. Three categories of respondents based on domains of difficulty (Community Mobility, Household Activities, and Personal Care) are used to illustrate how respondents negotiate their self-identities as independent in light of the other three factors.

Independence and dependence are concepts frequently associated with aging and with chronic illness and disability. Researchers from a number of traditions have approached issues of independence and dependence from a variety of perspectives. Literature from a biomedical or epidemiological perspective tends to emphasize measuring the amount of assistance needed with tasks; gerontological literature tends to focus on issues around caregiving; while the disability literature highlights issues of autonomy, rights and the imposition of dependence on persons with disabilities.

Despite the widespread emphasis in research and policy on independence and dependence, particularly for older adults, little attention has been paid to examining perceptions of independence and dependence from the perspective of the person with the chronic illness or disability. People’s subjective perceptions may have implications for their morale and adaptation to chronic illness as well as for their attitudes towards service utilization and for their help-seeking behaviours (Gignac & Cott, 1998). Moreover, an individual’s subjective perceptions may differ from the subjective perceptions of health care professionals and family, potentially creating conflict around decisions about living circumstances and service use. For example, in her work on the social construction of frailty, Kaufman (1994) provided numerous examples of situations where the subjective perspectives of older adults, their families and care providers were at odds with one another. Further, little is known about the implications of losses of independence or dependence for the identity of persons with a physical disability, despite literature suggesting that independence and dependence may be important components of older adults’ self-identities (Charrez, 1995; Kaufman, 1986).

The purpose of this research is to understand: (1) the subjective perceptions or meanings of independence and dependence of community-dwelling older adults with physical disabilities resulting from musculoskeletal disorders, specifically osteoarthritis (OA) and/or osteoporosis (OP); and (2) the factors that contribute to older adults’ self-definitions as independent.

Background Literature

Most of the research on independence and dependence for older persons has focussed on individuals with profoundly disabling conditions such as strokes or Alzheimer’s disease; much less attention has been addressed to individuals with musculoskeletal disorders. However, issues of inde-
dependence and dependence for persons with musculoskeletal conditions are important when the prevalence of these conditions and associated disability are taken into account. Musculoskeletal disorders are among the most prevalent chronic conditions in the Canadian population and account for a large proportion of all disabilities (Badley, Rasooly, & Webster, 1994). Approximately 53 per cent of the Canadian senior population reported having arthritis and/or rheumatism in the 1991 General Social Survey (Asche, Coyte, & Chan, 1996) and, in the 1990 Ontario Health Survey, musculoskeletal disorders were the most prevalent conditions causing disability among seniors (Badley et al., 1994).

Despite frequent use of the terms independence and dependence in the literature, they are rarely defined explicitly. Instead, they are used with the assumption that their meanings are clearly understood and universally accepted. When defined, dependence is treated as a state where one is reliant on others to achieve one’s goals. Dependence occurs within a social relationship and arises as an interaction between an individual and his or her physical and social environments (Anderson, 1971; Bond, 1976; Braden, 1991; Wilkin, 1987). Although independence is sometimes treated as an antonym of dependence and hence, can be defined as the absence of assistance from others, definitions of independence often refer to the ability to exert control over one’s lifestyle, activities, friendships, needs and goals (Martin Matthews & Shipsides, 1989; Marshall, McMullin, Ballantyne, Daciuk, & Wigdor, 1995; Wigdor & Plouffe, 1992).

Studies of independence and dependence reflect the diverse research traditions from which they arise. For example, much of the work on dependence stems from biomedical and epidemiological research on disablement, and the role of chronic illness and disability in creating conditions that can result in increased reliance on others. When measuring dependence, researchers primarily assess the type of assistance needed from others (e.g., personal care, transportation, finances) and whether assistance is, in fact, received. Details about who provides the assistance and the nature of that assistance are often overlooked, despite research on caregiving for older adults that indicates that these factors have important implications for care recipients and providers (Brody, 1981; Brody, Johnsen, & Fulcomer, 1984; Cantor, 1979). Research on independence typically stems from sociological and gerontological work on aging and disability. It emphasizes psychosocial variables related to dependence, such as people’s attitudes and level of social support, as well as economic, political, and social environments that may reinforce or perpetuate dependency (Barnes & Oliver, 1995; Hahn, 1994; Pfeiffer, 1994; Stone, 1984; Williams, 1991). Neither focus emphasizes the implications of physical independence and dependence for self-identity.
Theoretical Perspective

We frame our study within the context of symbolic interactionism. According to the symbolic interactionist perspective, meanings are the subjective understandings that people attach to various situations or symbols. These meanings develop through social interactions and reflect individuals' subjective definitions of their situations (Blumer, 1969). People, therefore, actively construct, negotiate, and modify social experiences, roles, and identities. According to the interactionist perspective, having a chronic illness is an unfolding or emerging process that occurs over time (Bury, 1988; Corbin & Strauss, 1988) and involves a process of adaptation that includes physiological, psychological, social and economic changes (Char- maz, 1995; Corbin & Strauss, 1988). Different theorists have identified phases of living with a chronic illness, beginning with the initial disruption of having a chronic illness or disability, followed by learning to manage the chronic illness and finally by adapting to living with chronic illness (Bury, 1991; Charmaz, 1995; Corbin & Strauss, 1988). As with other chronic conditions, living with OA and OP can be characterized by disruption, followed by increased efforts to manage the illness, and finally, by adaptation to the condition. Throughout these phases the person with chronic illness must deal with uncertainty, cope with stigmatization, do biographical work and recompose a sense of identity (Carricaburu & Pierret, 1995).

Illness poses a threat to a person's self-identity and interaction with others (Fife, 1994). With chronic illness and disability, one is no longer able to perform roles and activities in the same manner as prior to having the condition. Persons with chronic illness have to negotiate to incorporate these changes in role performance into their everyday lives and self-identity. As Kaufman (1993) writes, “In illness, the self may be examined, redefined, and questioned, but it always remains the existential framework for dealing with the debilitating effects of disability and limitation” (p. 14).

In this work, we are specifically interested in how people incorporate meanings of independence and dependence into their self-identity. We draw on Charmaz's (1983) concept of identity goals to conceptualize subjective perceptions of independence and dependence as specific identity goals affected by chronic illness. That is, being independent or not dependent are identities that persons with chronic musculoskeletal conditions value and will actively seek to achieve or maintain. When threatened by a chronic illness, people will make efforts to maintain or re-establish their identity as independent.
Method

We used a qualitative descriptive approach using semi-structured, in-depth interviews and following standardized guidelines set out by Miles and Huberman (1995).

Sampling Procedure and Sample
A combination of theoretical and purposive sampling strategies was used (Miles & Huberman, 1995; Patton, 1990). We were interested in the perceptions of independence and dependence of older adults with moderate physical disability. We defined disability as “experienced difficulty doing activities in any domain of life (the domains typical for one’s age-sex group) due to a health or physical problem” (Verbrugge & Jette, 1994, p. 4). We used a modified version of the Health Activities Questionnaire (HAQ) (Fries, Spitz, Kraines, & Holman, 1980) to screen for physical disability. Respondents were eligible to participate in the study if they reported difficulty in performing at least three activities on the HAQ. The boundaries of the data collection were, therefore, age (at least 50 years), diagnosis of OA and/or OP, and sufficient physical disability as a result of these conditions to have at least some difficulty performing activities of daily living.

Respondents were identified through a variety of sources including rheumatologists, family physicians and home care agencies, as well as advertisements in community agencies and seniors centres. All participants were screened over the telephone prior to the interview to ensure that they had been diagnosed with osteoarthritis and/or osteoporosis and that they had physical disability associated with their musculoskeletal condition and not as a result of a co-morbid condition.

Twenty-seven respondents were interviewed of whom 12 had OA, eight had OP, and seven had both OA and OP. Twenty-two participants were female and five were male. Respondents ranged in age from 52 to 89 years, with a mean age of 72 years. Fifteen respondents were married and 12 were either widowed, separated, or never married. Eleven participants lived alone, 13 lived with their spouse or an adult child, and three lived with their spouse and adult child(ren). Twelve participants lived in apartments and 15 lived in houses or townhouses.

Data Collection
The interviews were conducted in the greater Metropolitan Toronto area by the first author and a research associate, both of whom had previous experience in qualitative interviewing. Informed, written consent was obtained prior to each interview. The interviewers followed an interview guide that contained a series of questions that encouraged respondents to describe their everyday experiences living with OA and/or OP and their thoughts and feelings about their independence. Some examples of the questions asked are: “Would you say that your life has changed since you
have had OA/OP?"; "Can you tell me what a typical day is like for you now?"; "How independent would you say that you are now?"; "What does being independent mean to you?". The interviewers were free to vary the exact wording of specific questions and the order in which they were asked. Probes for detail were used and varied in each interview. Each interview was approximately 60 to 90 minutes in length. All interviews were taped and transcribed verbatim. Reliability of the data collection (Miles & Huberman, 1995) was monitored by the first author who reviewed the tapes and transcripts on an ongoing basis, and met frequently with the research associate, to ensure consistency in the interviewing technique. At the end of each interview, the interviewers recorded field notes of their general impressions which were also transcribed and included in the data sets.

Data Analysis
Data analysis began concurrently with data collection and guided the sampling. The coding scheme was developed in an iterative, inductive manner. To begin, the first author and research associate open-coded three transcripts independently, after which they met to compare and contrast codes that emerged from the data and to develop a coding scheme. The two met frequently to ensure consistency in the definitions and interpretations of codes. It was determined that, with one exception (fractures), the same codes were applicable to both OA and OP. Once a satisfactory level of inter-coder reliability was established, each interviewer coded approximately half of the transcripts.

In the first stage of the analysis, the data were explored for themes underlying meanings of independence. For example, relying on others was treated as a separate theme from control, choice and freedom. As the analysis proceeded, it became evident that while there were common themes underlying definitions of independence, respondents differed in their self-definitions as independent. These differences appeared to be related to levels of disability, use of assistive devices, coping strategies and nature of the helping relationship.

In order to explore these findings further, we first categorized respondents with respect to their disability levels according to five domains of difficulty that had emerged from the data. Categorizations of respondents were based on two independent rankings by the interviewers. Each transcript was reviewed and respondents ranked for each of the five domains of activity as to whether: (1) they had no difficulty with those activities; (2) they were modifying the way that they did activities in that domain; (3) they needed help from others or used assistive devices for activities in that domain; or (4) they were unable to do activities in that domain. From these rankings, three categories of respondents based on physical difficulty emerged. The five domains of difficulty and three categories of respondents are described in detail in the results section.

Next, data matrices (Miles & Huberman, 1995) were developed that allowed systematic comparison of the respondents in the three categories.
of disability with respect to their perceptions of the meanings of independence and dependence, of their condition and its effect, if any, on their independence, of their use and perceptions of assistive devices, their support networks, and their coping efforts.

Throughout the data analysis, a number of steps were taken to ensure the trustworthiness of the analysis. In order to ensure objectivity/confirmability (Miles & Huberman, 1995) an audit trail was maintained and reviewed by the second author to ensure that conclusions and assumptions in the analysis were supported by the data. Internal and external validity (Miles & Huberman, 1995) were addressed at various stages of the analysis when the results were presented to the project’s research advisory committee, which included health professionals, advocates and consumers, and groups of arthritis health professionals and consumers.

Findings

The value placed on independence was reflected in the importance our respondents attached to being independent. They used biography to emphasize how important independence had been for them throughout their lives, and emphasized how they had always strived, and continued to strive, to be independent. Said one woman, “I have to be independent. That is the way I am. I’ve worked all my life and come home and did my work at night. I never depended on anybody and I really don’t like to let other people do my work, you know. You get used to your own little way” (Mrs. J.L.). Being independent has always been part of their self-identity and was now threatened by the demands placed upon their physical health by their OA and/or OP. The respondents’ desire to remain or to re-establish their independence was inherent in their descriptions of how they went about their day to day activities and attempted to cope with their condition. Being independent was an identity goal that they were actively struggling to maintain.

Our findings indicated that while respondents shared similar overall definitions of independence and dependence, how they applied these definitions to their own situation to define themselves, personally, as independent or dependent, was conditional on four factors. These factors interacted to influence an individual’s self-definition as independent or dependent. In order to illustrate this complexity, the findings are presented as follows: first, the two main themes underlying shared overall meanings of independence and dependence are outlined; second, the four conditional factors for self-definition as independent are described; and, finally, three cases are presented to illustrate the interaction of the four conditional factors.

Shared Meanings of Independence and Dependence

Respondents did not always differentiate between independence and dependence in common parlance. At the same time, there were two main
themes underlying their meanings of independence and dependence. The first theme related to relying on others, or more specifically, to dependence. All of the respondents talked about not having or not wanting to rely on others or about doing as much as they could for themselves as important components of independence. In this sense independence and dependence were treated as antonyms, with the reliance on others for help signalling a loss of independence. A typical statement reflecting the responses of many participants was that independence “means that I do my own things. I do not like to be dependent on anyone” (Mr. J.S.).

The second theme was related more specifically to independence. In addition to talking about relying on others, half of the respondents also talked about choice, control and freedom as important components of their independence. Specifically, they believed that their musculoskeletal condition had affected their independence by taking away their freedom to do what they wanted to do when they wanted to do it. For example, one person noted that, “For me, being independent is being able to do anything I want at any time without having to think about needing any help. And I don’t have the choice now to do anything I want when I want, and I always have to think about other things. The choice is taken away” (Mrs. V.M.). Needing to rely on others for help was secondary to the meaning of independence here; it was the loss of control and freedom in people’s lives that was central.

This loss of personal control came not only as a result of increased reliance on others (Fife, 1994), but also as a manifestation of the uncertainty that characterizes the trajectory of many chronic conditions (Wiener & Dodd, 1993; Stewart & Sullivan, 1982; Pinder, 1990; Yoshida, 1997). It went beyond having to rely on others; it also reflected the loss of ability to rely on one’s body. Previously taken for granted abilities were no longer available, threatening the person’s freedom and self-identity as independent (Charmaz, 1995; Oleson, 1990). Hence, it was not reliance on others that was defining their lack of independence, it was the lack of reliability of their own body.

These two main themes, relying on others, and choice, control and freedom, underscored most of the respondents’ perceptions of their independence and dependence. However, although respondents shared these similar overall meanings of independence, whether they defined themselves as independent was conditional on four factors: (1) domains of difficulty; (2) their coping efforts; (3) the use of assistive devices; and (4) the nature of the helping relationship. These four conditional factors will be described in turn and then illustrated in three cases representing the three categories of respondents that emerged from the data.

(1) Domains of Difficulty
Participants described five domains of physical activity in which difficulties arose as a result of their condition (See Figure 1). The first domain was
Figure 1 Domains of Difficulty

- **Personal Care**
  - bathing
  - dressing

- **In-Home Mobility**
  - walking in home
  - stairs

- **Household Activities**
  - housekeeping tasks
  - home maintenance

- **Community Mobility**
  - getting out into community
  - drive car

- **Valued Activities**
  - sports
  - recreation
  - leisure
valued activities in which respondents described difficulties with activities like sports or recreation (e.g., golf, gardening), and leisure activities such as travelling, shopping for pleasure, going out with friends and entertaining. Problems within this domain included being able to sit, stand, or walk for extended periods of time, pain and stiffness when engaging in hobbies and fatiguing quickly. The second domain of difficulty was community mobility which encompassed activities like getting out of the home to go shopping or run errands. Of particular importance in this domain was the ability to drive a car. The third domain was household activities which included difficulty with housekeeping tasks, particularly vacuuming and meal preparation, and difficulty with household maintenance tasks like yardwork. The fourth domain of activity was in-home mobility and included the ability to get around in the house in terms of walking and negotiating stairs. The final domain was difficulty with personal care such as bathing, dressing, getting in and out of a bathtub or shower, and getting up from a toilet.

These five domains can be conceptualized as a hierarchy of increasing disability from valued activities to personal care. That is, a person who reported having difficulties with personal care also reported difficulties in each of the other four domains. However, although people with difficulties in community mobility often reported limitations in their valued activities, they did not necessarily have problems with activities in the remaining domains. These findings are similar to those of Badley, Rothman and Wang (1998) who found that physical dependence in external household, domestic and personal care activities formed a hierarchy in that each level of physical dependence included the level(s) above it. Although our findings refer to difficulty in performing activities rather than physical dependence, the activities included in the various categories of the two hierarchies are similar.

Perceptions of self as independent varied depending on the level of disability of the respondents. However, these variations did not always correspond linearly with increasing disability. That is, greater disability did not necessarily mean greater reported loss of independence. This phenomenon will be illustrated later in the three cases after the other three conditional factors have been described.

(2) Coping Efforts
When respondents initially encountered difficulties with an activity in any domain, their first response was to continue to perform the activity themselves, often by modifying it slightly, or by exerting more energy, or by spending more time on it. Respondents described becoming more efficient in their performance of activities; doing laundry once every week or two and preparing one or two large meals and freezing portions for later use. One respondent said:
Well, if I do any kind of work on the sink I open my door and I put one leg inside the cupboard because that eases my back. And I'm not as fussy anymore about cleaning house so it's just that's not that important to me anymore. I try not to get overtired, like pushing beyond what I want and can do because I find my arthritis flares up more if I do more than I normally do, so, I have slowed down. (Mrs. M.J.)

When small modifications and increased time and energy were not enough to surmount difficulties with activities, respondents used a variety of coping efforts directed toward problem-solving. For example, when *community mobility* was hampered, some respondents shopped further away from their homes, but in stores or malls on bus routes or where they could park closer to their destination. When *household activities* like laundry were affected by OA or OP, several respondents told us that they spent the better part of a day reading in their basement or watching television while doing laundry. In this way, they avoided repeatedly going up and down stairs.

Most of these problem-solving coping behaviours were strategies specifically aimed at maintaining one’s identity as independent. Respondents expressed pride in their personal coping strategies; they were evidence of accomplishment, not increasing disability. One person noted, “You learn to do a lot of things that you normally wouldn’t do” (Mrs. R.Y.). Moreover, when people found that they could not compensate for their difficulty, they sometimes preferred to forego the activity and tolerate unmet needs rather than seek assistance from others. This was especially true for *valued activities*, activities around *community mobility*, and *household activities* other than meal preparation.

In addition to these problem-solving coping efforts, respondents also used a number of emotion-focussed coping efforts, such as perseverance and acceptance. For example, they told us that they continually exhorted themselves to persevere and they struggled to sustain their energy in coping with their condition. As one said, “I thought, I can’t keep going,” but when you know that you have to ... you do it” (Mrs. M.C.). Other emotion-focused efforts included positive framing or downward comparisons. As one said, “Others have it worse than I have, so cheer up” (Mrs. P.M.).

3) Assistive Devices
As difficulty performing activities increased, modifying activities or tolerating unmet needs was no longer sufficient and respondents turned to assistive devices to manage their disability in different domains. They described a wide range of assistive devices that they utilized. For example, buttonhooks, long handled shoehorns and combs, grab bars in bathrooms, bathseats, and raised toilet seats were used to assist with *personal care*. Jar openers, reaching devices, and a variety of labour saving appliances,
like microwaves, helped with *household activities*. Walkers, canes, wheelchairs, and scooters were used for *community* and *in-home mobility*.

In general, relying on assistive devices was not seen by respondents, as being dependent but rather, as a means of maintaining independence. However, perceptions varied depending on: whether the device being used was normalized or stigmatized; and, whether the person had actually used the device or was only considering its use. Stigma refers to anything that disqualifies individuals from full social acceptance, regardless of whether people are responsible for their condition (Goffman, 1963). Hence, if an assistive device is normalized, stigma is minimized (Pippin, 1996). Moreover, because the persons who use the device often shares the same beliefs about it as others, they also typically perceive the device as stigmatizing or not, based upon these shared beliefs (Goffman, 1963). Many of the gadgets used to help with *household activities*, such as jar openers or reachers, were normalized. These gadgets were commonly used by older persons, whether disabled or not, and they were not perceived as connecting the social identity of the user to a negative attribute. Further, they were not usually used in public but were used for brief periods of time in the relative privacy of one’s home. Using these devices was not perceived negatively and was associated with decreasing dependence by decreasing reliance on others. “I cannot use a kitchen stool, if I need anything off the shelf somebody else has to get it down for me, although I do have a reaching aid with which I am able to get a certain thing down which I couldn’t otherwise and then I don’t have to be that dependent on other people” (Mrs. M.C.).

More stigmatizing were devices such as walking or mobility aids, particularly wheelchairs (Rush & Ouellett, 1997). These assistive devices were seen as evidence of dependence rather than independence, particularly if the person had not used the device yet and experienced its benefits. Mobility aids were the greatest threat to a person’s self-identity as independent because they were used constantly and were kept with the person at all times, clearly labelling the person as disabled. Several respondents described how they initially resisted using canes or walkers because they felt that they would look old or disabled. They attributed this reluctance to pride or vanity. Particularly difficult for respondents was having to use a device for *community mobility*. “It takes a lot of courage to start using a walker. It’s very hard to start using those things and go out in public with them but you’ve just got to make up your mind that you’re going to do it” (Mrs. M.C.). Using the device clearly identified the person as different from others. Many female respondents described how they would prefer to hold someone’s arm when outside rather than use a cane or walker. Holding onto someone’s arm was not considered out of the ordinary for women, and therefore their self-identity as independent was not as threatened as by using a mobility aid. People’s experience using mobility aids was also important to their perceptions of themselves as independent or dependent.
Respondents who felt that using a mobility aid was evidence of dependence were less likely to be have actually used these devices. In contrast, respondents who used mobility devices regularly usually viewed them as providing independence. As one respondent said, “And now I don’t know how I ever did without it [walker]” (Mrs. T.D.). These respondents may continue to see the device as stigmatizing, but their goal of maintaining their independence was so important to them that they were willing to risk stigmatization.

(4) The Nature of the Helping Relationship

As indicated by the two main themes underlying overall shared meanings of independence, relying on other people was usually perceived as dependence by respondents. However, perceptions were related not only to help being received, but also to the relationship between the help provider and the help receiver, as well as the domains for which help was given. For example, relying on a spouse for any help other than personal care and in-home mobility was usually not considered dependence. Spouses were seen as extensions of the person, especially for tasks in the household activities and community mobility domains, like carrying things up and down stairs, assisting with meal preparation, and providing transportation. Self-identity as independent was not threatened by having spouses perform these tasks because these roles might normally be shared. However, there existed important gender and cultural issues to consider within this cohort. Female respondents described feeling guilty when their husbands did laundry and prepared meals if they had never been involved in these tasks before. Their identity as independent was threatened in these instances because their spouses were taking on roles that were gender stereotyped and that would usually have been performed by them, thereby drawing attention to their difficulties with role performance.

There were also instances when relying on people other than one’s spouse were not perceived as dependence, like hiring someone to do household activities such as outdoor maintenance or housekeeping. In these instances participants exchanged money for services and retained control over the timing and extent of help, thereby maintaining their identity as independent. However, needing assistance, paid or unpaid, with personal care activities, particularly bathing or dressing, was viewed as increasing dependence. These perceptions of increased dependence occurred regardless of whether the help came from family members, from friends, or from service providers and they were associated with a loss of control and the ability to care for oneself. Performance of these roles without assistance is so culturally and socially defined as independent adult behaviour, that receiving any kind of assistance was a threat to identity as independent. Consequently, maintaining independence in the personal care domain was of utmost importance to all respondents. As one person noted, “Independence means being able to look after myself. I mean ... thank goodness I’m still washing myself ... I don’t mind even using a
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**Figure 2** Selfdefinitions as independent

scooter or a wheelchair, but as long as I can take care of myself, like what I meant was personal care” (Mrs. R.Y.).

**Self-Identity as Independent**

The four conditional factors, described above, all play a role in shaping people’s self-definitions of their independence and dependence. This complex phenomenon will be examined for three categories of disability evident amongst our respondents: **Community mobility, Household activities and**
Personal care (see Figure 2). As mentioned earlier, we selected respondents who reported difficulty with at least three activities on the HAQ (Fries et al., 1980). As a result, we did not interview anyone with difficulties solely in valued activities. Further, although difficulty with in-home mobility and personal care emerged as separate domains of difficulty, most respondents who had difficulties in one had similar difficulties in the other, so we included all of these respondents in one category of Personal Care.

People's self-definitions as independent varied depending on the level of disability of the respondent. However, these variations were not entirely explained by increasing disability. That is, as disability increased to encompass more domains, people's perceptions of a loss of independence and increased dependence did not necessarily match this increased disability. Further, as suggested earlier, disability in certain domains was more of a threat to self-identity as independent than others. Each of the three categories of disability was associated with differing perceptions and definitions of independence reflecting the interaction of the other three conditional factors.

(1) Community Mobility Category
Respondents in the Community mobility category often had made numerous modifications to their hobbies, leisure pursuits, and plans to socialize or travel. Typically however, they still were able to get out into the community either on their own or with some assistance from others. Occasionally, they reported difficulties accomplishing household activities, but the major issue for them with respect to their independence was being able to get out of the house into the community. For example, one respondent said, "Well, [independence] means you can do just about anything on your own, you don't need anybody around or you don't need assistance with crutches or a wheelchair or something like that. Like that would be physical independence, you know, that you can go and do activities without depending on other people" (Mr. R.M.).

The case of Mrs. Jones typifies that of a person whose disability is at the Community mobility level:

Mrs. Anne Jones is a married woman in her late 50's living in a one-storey house with her husband. She has three children, two of whom live in a neighboring community, and a third who lives in another province. She has had arthritis in one knee for years but in the past two years her other knee, her hands and her neck also have been affected. She believes that she is less independent because of her arthritis. She describes having difficulties in walking, particularly going up and down stairs, and she uses a walker when she goes out. Although she describes some difficulties doing household activities, such as laundry which involves carrying things up and down to the basement, her major concern in terms of her independence relates to her ability to get out of the house to go shopping and to go to the theater. She does not
drive and prior to her arthritis this was not a problem for her; she was able to walk to the shops or take a bus. Now she must rely on her husband for a ride whenever she wants to go out. For her, this represents a loss of independence. She describes the most difficult part of having osteoarthritis as not being able to always go out when she wants to go out. She says about her loss of independence, “I’ve got to the point where I know that I do have to depend on other people quite a bit”.

When discussing their independence, Community mobility respondents talked about being able to do what they wanted when they wanted. They had reached the point where their problem-solving strategies of modifying activities or tolerating unmet needs were no longer sufficient to address their disability. Increasingly, they needed assistance from others to help with tasks that were threatening to their self-identity and they anticipated the need to use potentially stigmatizing assistive devices. Often they had begun to rely on others for assistance with activities such as transportation and they felt constrained by this. These individuals were striving to accept their condition, but they found it difficult to do so and had not come to terms with it. As one said, “When things are forced on you, I find it very hard to accept” (Mrs. J.L.).

Community mobility respondents felt that their independence had been greatly compromised by their condition. In explaining why they believed this to be the case, they were most likely to compare their current physical condition to their abilities prior to having a musculoskeletal disorder. Currently, they were unable to do the things that they wanted to do without relying on others, and they did not feel that they had as much control over their bodies as they had previously. Because they used their level of ability prior to having their chronic condition as the yardstick for being independent, they ended up focussing on their losses, compromises, and their reliance on others in determining that they were no longer independent.

(2) Household Activities Category
Respondents in the Household activities category of disability generally had given up or restricted most of their valued activities and got out into the community rarely and usually only with the assistance of formal transportation services. They sometimes had difficulties with in-home mobility, particularly stairs. They often needed to use a cane or walker as well as assistive devices to help with meal preparation. Respondents in this category are typified by the case of Mrs. Smith:

Mrs. Betty Smith is a 73 year old married woman who lives in a condominium apartment with her husband and son. She began having health problems about five years ago when she began to fatigue easily. She was eventually diagnosed with osteoarthritis in her knees, shoulder and hands. She describes herself as quite independent. She uses a walker around the house and a scooter for her
occasional excursions into the community to go to her pool class and doctor’s appointments. She has stopped going out socially because she is no longer able to reciprocate for social visits. She cannot entertain people in her own home and she does not feel comfortable always going to other people’s homes to visit. Her husband and son are both employed. She continues to do the cooking for the family, although she does not prepare as many dishes as she used to. She receives help from a social service agency for the household cleaning and laundry. She needs some assistance to get in and out of the bathtub. She considers herself to be independent because she says that she does not rely on anybody. “My husband is also old and works from morning to evening. I don’t ask him to do anything. Whatever I do, I do it on my own without asking my son or my husband to do anything.”

These respondents’ perceptions of their independence revolved around managing household activities, such as meal preparation and housekeeping in the case of women, and household maintenance in the case of men. According to one respondent, “Being able to get up everyday and cope with the little simple things like meals, and do a little bit of dusting and tidying up and that, that’s all [independence] means” (Mrs. E.P.).

When Household activities respondents talked about independence, they talked about being able to do what they needed without relying on the assistance of others. To avoid relying on others, these individuals had given up many valued activities and were now mainly concerned with maintaining their household, which they were able to do without assistance from others, albeit with difficulty. They often used a variety of assistive devices, including mobility devices. Typically, they had used these devices for sufficient time to feel that they helped maintain their independence. Most of their coping was directed toward efforts to accept their condition. As one person said, “You learn to live with it” (Miss L.M.). Generally, participants in this category did not talk about a loss of freedom or control when they talked about independence, and they did not compare their current physical state with their pre-illness state.

One might expect that these respondents’ identities as independent would be even more compromised than the Community mobility respondents due to their greater disability. However, most of these respondents did not perceive that their independence was greatly affected by their condition. Their reference point for defining their independence was no longer their pre-illness abilities. Instead, when they thought about their independence, they considered only the activities that were necessary in order to take care of themselves and their household. Since they were able to manage these without relying extensively on others they perceived themselves as independent. In other words, their self-definitions of independence were a reflection of their current capacity to manage essential activities in their lives.
These differences in definitions of independence illustrate how individuals incorporate different levels of disability and different roles into their definition of the situation. These individuals do not define independence in terms of their functional abilities prior to their chronic condition and so they are able to preserve or re-establish their identity as independent. This new definition and context allows them to achieve their identity goal of being independent. Other research has also shown that people will lower their identity goals until they match their lessened capacity as a means of adapting to chronic illness (Charmaz, 1995).

(3) Personal Care Category

Personal care respondents were no longer able to perform household activities without assistance from others. Their in-home mobility was limited and, in addition to using a walker, they often needed a wheelchair for longer distances. They described difficulty with dressing and getting in and out of the bathtub. The case of Mrs. Clarice Wells typifies this category of respondents:

Mrs. Clarice Wells is a 63-year old married woman living in an apartment with her husband. She has had OA for over 20 years and was diagnosed with OP approximately 13 years ago. She is unable to walk unassisted or manage stairs on her own. She refuses to use a walking aid when she goes out because she says she is very proud. Instead, she relies on her husband for everything. He helps her to walk and he does the cooking, shopping, and cleaning. Once a week a homemaker comes in to help her bathe. She feels that her condition has affected her independence in every way because she always needs her husband or someone else to help her with just about everything she does. She defines independence as being able to plan and do things by yourself.

These respondents’ perceptions of their independence centred around getting around their home and looking after their personal care needs, such as dressing and bathing. A participant with OA noted, “I think to use the word independent would be not having to worry or want the help of anybody, you know, you can do everything by yourself. You can get through whatever you want to get through on your own strength. That’s what I would call independent” (Mrs. Y.C.). Personal care participants talked about independence in terms of being able to do what they had to do without relying on others for help. However, they usually received assistance from others for household activities such as cleaning and meal preparation and they struggled to perform their own personal care activities.

Personal care respondents were less likely to use the variety of problem solving strategies that were used by people with disabilities in other domains. In fact, what little problem solving they engaged in was directed almost entirely toward managing the pain and stiffness of their chronic illness, and not toward modifying or changing the ways that they handled
tasks. Help from others was required to accomplish most of these activities. Instead, their coping efforts were directed primarily toward dealing with the emotional side of their condition. For them, the situation had progressed to the point where they could no longer maintain their identity as independent and their coping efforts were now directed at minimizing their losses or at feeling better about the threat to their identity. For example, virtually all the Personal Care respondents used positive framing and many used downward comparisons as a way of coping. As one person said, "Tomorrow is another day. We'll see what it brings, so don't worry about the pains of tomorrow" (Mrs. D.N.). The increased use of emotion-focussed coping by the Personal Care respondents reflects their lack of control over their illness. According to Lazarus and Folkman (1984) problem-solving coping is usually used in situations where people have some control over the situation whereas emotion-focussed coping is used more often when people have little control over their circumstances.

These respondents were no longer able to maintain their self-identity as independent even by lowering their identity goals. Their reference point for their definitions of self as independent was their current level of ability which meant that they relied on others for assistance. They recognized their need for continued assistance from others and did not define themselves as independent.

Discussion and Conclusions

Our findings extend the literature on independence and dependence by going beyond work on functional limitations with ADL and IADL and by qualitatively examining the meanings of independence and dependence for seniors with musculoskeletal disorders. Our work reveals several important findings. First, returning to the symbolic interactionist perspective, independence is an important aspect of self-identity for older adults with musculoskeletal conditions. Second, respondents actively work to renegotiate and redefine their meanings of independence in order to maintain their identity as independent. And third, people's perceptions of their independence and dependence do not correspond in a simple linear fashion to their level of disability but are conditional on domains of disability, coping efforts, use of assistive devices and the nature of the helping relationship.

Our findings highlight a process of adaptation to increasing disability in terms of changing expectations and acceptance in ways that complement other research on chronic illness in the symbolic interactionist tradition (Bury, 1991; Corbin & Strauss, 1988; Charmaz, 1995). For example, changes in definitions and meanings of independence reflect the difference between struggling with and struggling against chronic illness (Charmaz, 1995). When people struggle against chronic illness they hope to regain past identities and their coping efforts are directed towards returning
themselves to their previous level of ability. When people struggle with chronic illness they struggle to keep their bodies functioning as best they can and therefore they can define their lives as normal as possible. Respondents who were struggling against their condition (those in the Community Mobility category) described a greater perceived loss of independence than those who were struggling with their condition (those in the Household Activities category). This was the case even though the latter group reported greater disability. That is, individuals who reported greater disability did not necessarily report greater losses to their self-identity as independent. Instead, people's identity as independent was related both to their level of disability and to their ability to accept that disability. Robinson (1993) also describes how individuals with chronic illnesses minimize the significance of the impact of their condition and reconstruct the reference points by which they judge the experience in an attempt to normalize the experience. However, we found that the strategies of lowering identity goals and struggling with chronic illness had limited success in maintaining self-identity as independent for our most disabled respondents (those in the Personal Care category).

These differences in emphasis in definitions of dependence and independence suggest several conceptually interesting hypotheses for future research. For example, it is possible for people to conceive of themselves as both dependent and independent, as in the case where a person is physically dependent on others for assistance with a specific task or activity, yet still retains control over who helps, or the timing and amount of help received. Alternatively, a person may report a loss of control over the ability to perform tasks (i.e. less independence), but not receive assistance from others (i.e. no dependence). In such situations individuals may forego the activity, give up future plans, or make do with less (Gignac & Cott, 1998). Finally, Baltes' (1996) work suggests that dependence on others can be adaptive. Specifically, she discusses instances where individuals choose to be dependent on others for some activities in order to remain independent in other areas of their lives. It is not clear in such instances whether individuals would subjectively perceive themselves as dependent, because they received help, or as independent, because they exercised control over the nature of that help, or, as suggested above, whether they would perceive themselves as both independent and dependent. Future studies of the meaning of independence and dependence in terms of people's identity should be expanded to include such cases.

Verbrugge (1990) identifies three domains of disability including obligatory activities (e.g., personal care and household activities necessary for independent living), committed activities (e.g., homemaking, child care and employment) and discretionary activities (e.g., leisure pursuits, socializing and hobbies). The primary domain of disability addressed in the literature is often obligatory activities, particularly personal care and particularly for those individuals at risk of institutionalization. Our find-
ings highlight the importance of issues of independence and dependence for community-dwelling older adults who are living day to day with physical disability that involves domains beyond personal care such as committed and discretionary activities.

Typically, the results of qualitative research are not generalized to other populations. However, our findings may also have relevance for other community-dwelling older adults. The shared meanings underlying overall definitions of independence probably have relevance for many older adults, whether or not they have physical disabilities. For example, many participants discussed their independence as a characteristic of their self-identity prior to their chronic condition. Hence, relying on others or losses to control might threaten a person's independence even in the absence of a chronic condition. Further, we focussed on the consequences of OA and OP in terms of the disability that ensues from them, rather than focussing on the impairments associated with those conditions. As a result, many of the issues surrounding changing definitions of self as independent for those with increasing physical frailty and increased reliance on others could apply to older persons experiencing declines in their physical functional abilities, regardless of the underlying cause of that decline. Finally, considering the prevalence of musculoskeletal disabilities (and particularly arthritis) in the elderly population, one can argue that these findings have relevance for many older adults.

The finding that perceptions of self as independent vary by the domain of difficulty, the use of assistive devices, the nature of the helping relationship, and coping efforts, and, that self-definitions of independence do not always correspond with increasing disability, are extremely important for research on independence and dependence. Generally, independence and dependence are operationalized by the amount of assistance required to perform ADL and IADL. According to these criteria, an external observer would categorize the Personal care group as dependent, the Household activities group as somewhat dependent, and the Community mobility group as largely independent. However, these “objective” categorizations would not correspond to the subjective perceptions of respondents. Moreover, by organizing the domains of disability into a hierarchy, it is possible for people to perceive themselves as independent in some domains and as dependent in others. In addition, the domains of disability are not all weighted equally. That is, even infrequent assistance with personal care seems to be associated with subjective feelings of dependence and a loss of independence, whereas similar amounts of assistance in other domains are not associated with the same subjective perceptions.

Finally, our findings have relevance for the ways that independence and dependence are measured. Specifically, in some measures of ADL and IADL respondents are penalized for using an assistive device in that they are ranked as less independent. Little attention has been paid to how the use of assistive devices or environmental modifications might alleviate the
need for help from others (for an exception see Verbrugge, Rennert, & Madans, 1997). Our findings suggest that many respondents, once they begin to use these devices, actually perceive themselves as less dependent and more independent. The issues for independence become on who or what is the person dependent, to what extent and to accomplish what tasks?

Our findings also have relevance for policy and service delivery, particularly in terms of the timing and types of service provided. That is, augmenting a person’s own coping efforts with the appropriately timed introduction of assistive devices and use of services could enhance perceptions of independence and prevent the potential withdrawal and social isolation that could occur if seniors simply give up activities that they find increasingly difficult. However, it is important to keep in mind that the types of service provided will also have an effect on people’s independence. For example, performing one’s own personal care was very important to respondents’ self-definitions as independent, whereas, for many, having someone else perform household activities did not threaten perceptions of independence to the same extent. These findings may contribute to understanding the results of other studies where seniors put help with household tasks as most important to maintaining their independence, in contrast to formal service providers who ranked help with personal care as most important (Keating, Fast, Harlton, & Oakes, 1996). Our findings suggest that it is the ability to perform one’s own personal care that is most important for subjective perceptions of independence and therefore, older adults are more likely to accept assistance with household activities because this does not threaten their identity as independent to the same degree. It may also mean that by making personal care a prerequisite for receiving household services, we may actually undermine people’s sense of independence.

There are limitations to this study that suggest directions for future research. First, we interviewed respondents once and did not follow them over a period of time. We therefore were able to explore differences in the meaning of independence and dependence among our participants, but we were unable to examine changes over time. Second, we had very few male participants in the study. Although the results of the interviews of the men were similar to those of the women, it would be important to replicate the study with a larger sample of males. Third, we limited our study to seniors with moderate disability from chronic musculoskeletal disorders. Future work should examine meanings of independence and dependence for seniors with a range of disability and conditions. Finally, issues of independence are only one part of people’s identity that may be impacted by chronic illness. Some people have argued that an overly narrow focus on physical independence and an inability to accept one’s disabilities can lead to frustration and low self-esteem. Moreover, it can rob people of “true independence” by curtailing autonomy of thought and action (French, 1993). Consequently, future research on chronic illness not only needs to
expand definitions of independence to go beyond physical independence, but also needs to incorporate other aspects of people's identities.

References


