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The Psychosocial Impact of Rheumatoid Arthritis

by

Maria Joan Saary

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "The Psychosocial Impact of Rheumatoid Arthritis" submitted by Maria Joan Saary in partial fulfillment of the requirements for the degree of Master of Science.

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Date June 22, 1993

ABSTRACT

This study was based on three goals: (1) to replicate the age by intrusiveness interaction found by Devins et al. (1992), and validate a model of the psychosocial impact of chronic illness, (2) to assess whether perceptions of illness severity mediate or moderate relationships among disability, intrusiveness, and depression, and (3) to evaluate normative aging hypotheses in the context of rheumatoid arthritis (RA). Data was obtained from 65 RA patients who completed several questionnaires. The age by intrusiveness interaction was not replicated, and neither intrusiveness nor perceptions of severity mediated the disability-depression relationship. However, the disability-intrusiveness relationship was moderated by perceptions of illness severity. Neugarten's proposal that those experiencing off-time events would be more depressed was not substantiated, although trends were generally in the expected direction. Results affirm the importance of cognitive factors in the development of depression in an RA population.

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INTRODUCTION

Overview

Health, according to the World Health Organization, is "not merely the absence of disease, but complete physical, psychological, and social well-being" (WHO, 1958). Thus, physical, psychological, and social factors are intimately related. Clearly, illness affects not only physical functioning, but also psychosocial well-being.

The psychosocial impact of disease has been widely studied among chronic illnesses in general, and among rheumatoid arthritis (RA) populations specifically. Of particular interest has been the association between chronic illnesses such as rheumatoid arthritis, and depression. In fact, numerous models have been elaborated to explain this complex relationship, however empirical tests of such hypotheses have been replete with methodological difficulties. Furthermore, the association between illnesses like RA and depression is complicated by a variety of modifying/mediating factors. One such factor is illness intrusiveness, the extent to which an illness and its associated treatment(s) interfere with the performance of normal activities. However, in RA patients, the relationship between intrusiveness and depression was found to be indirect, varying as a function age (Devins et al., 1992). Several explanations of this finding have been proposed. Generally, the goals of this study were to verify the existence of an age by intrusiveness interaction among RA patients, and then to test the feasibility of a normative aging theory as an explanation for this occurrence. This study serves to integrate the health psychology and normative aging literatures, a worthy and valuable endeavour considering the need for integration in the provision of complete and effective health care.

Prevalence of Chronic Illness

In the earlier decades of this century, the major causes of illness were predominantly acute infectious diseases, many of which have subsequently been eradicated or controlled by advances in medicine. The consequence has been the emergence of chronic conditions as a major health concern (Rice & LaPlante, 1988; Strauss et al., 1984). Recent estimates suggest that as many as 50% of the population suffers from some type of chronic illness (Strauss et.al., 1984), and 14% are limited in activities as a result of such illness (Rice & LaPlante, 1988).

Although chronic illnesses are among the leading causes of death among both Canadian (Nagnur, 1986) and American adults (Burish & Bradley, 1983; Rice & LaPlante, 1988), mortality due to chronic illness in middle-aged and older adults has actually been declining (Rice & LaPlante, 1988). It appears that treatment efforts which increase survival without curing an illness, have boosted the prevalence rates of chronic conditions.

Furthermore, recent trends suggest that activity-limiting chronic conditions are becoming more frequent at earlier stages of life. Although older people are more likely to have a chronic illness, this is not merely an age-related problem. Among those aged under 17, 17-44, 45-64, and over 65, Strauss et. al. (1984) note the prevalence rates of chronic conditions to be .9%, 4.7%, 14.2%, and 39.5% respectively. In fact, 47% of the population experiencing illness-related disability are below the age of 65 (Rice & LaPlante, 1988).

Increasing concern among health care professionals with regard to chronic illness is justified. Decreasing mortality from chronic illness among the elderly, in the face of increasing prevalence, especially among younger age groups, means that more people are living longer with chronic illnesses. However, it is becoming apparent that

while a strictly medical model may be appropriate for dealing with acute illness, it has severe limitations with respect to the treatment of chronic illness (Burish & Bradley, 1983). To treat a chronically ill patient, the medical knowledge must be supplemented with psychological and social information that reveals the impact of the illness on the affected person's life (Strauss et. al., 1984).

Relationship Between Illness and Depression

Despite the occasional report of illness having a positive emotional impact (Liang et al., 1984), chronic illnesses more often have negative psychological concomitants. One of the most prevalent of these negative psychological correlates of chronic illness is depression (Katon, 1984). This association between illness and depression has been widely supported (Andrews, et al., 1978; Frerichs et al., 1982; Langner, 1963; Lipowski, 1975; Neff et al., 1980; Rodin & Voshart, 1986; Schwab et al., 1978).

There are primarily two methods researchers have used to investigate, in detail, the rates of concurrent depression and chronic illness. The first method is to assess the rates of medical illness in depressed patients. Neff, Husani, & McCorkel (1980) found that 88-97% of their sample of psychiatrically impaired persons in the general population had concurrent chronic physical illness. Kathol and Petty (1981) summarized several studies in which the frequency of concurrent medical illness among depressed patients ranged from 37-46%.

The second, and more common method of investigating the relation of interest, is to measure levels of depression in medically ill patients. Estimates of the prevalence of psychiatric disorders and depression among the physically ill vary widely from one study to another depending on the illnesses considered, the definition of psychological

distress, and whether one is considering inpatient or outpatient medical populations.

In a community sample, Wells, Golding, & Burnam (1988) found that among persons with one or more medical conditions, the prevalence of psychiatric disorder in the preceding 6 months, and lifetime prevalence respectively, were 24.7% and 42.2%, compared to 17.5% and 33.0% among those with no medical conditions. Wells, et. al. (1988) note that compared to cases in which there were no medical conditions present, concurrent medical conditions increased the risk of having a recent psychiatric disorder by 41%.

After examining several studies, Nielson & Williams (1980) conclude that among medical outpatients, the prevalence of psychiatric disorders ranges from 5-80% with most studies reporting figures from 5-29%, whereas the rates specifically for depression have been estimated to vary from 12-56%. For depression among medical outpatients, Rodin and Voshart (1986) quote studies with figures ranging from 12-36%, and Katon (1984) reports ranges from 12-25%.

Among inpatient medical populations, Cavanaugh (1984) suggests that prevalence rates for depression range from 22-32%, which is consistent with the range (20-33%) reported by Katon (1984). Kathol and Petty (1981) combined inpatients and outpatients, and concluded that the prevalence of depression in the medically ill ranged from 5-31% in various studies, but argue that a figure around 18% is most realistic. Condensing the previous discussion, it is clear that irrespective of the method used to assess the rates of concurrent depression and medical illness, a relationship unquestionably exists between these two factors.

Importance of Understanding the Illness-Depression Relationship

This relation between illness and psychological distress, particularly depression, has recently received

increasing attention in both the medical and psychological literatures. Understanding the co-existence of physical illness and psychological disorder is relevant for several reasons. First, clinical assessment of a physical condition is complicated by the presence of psychological disturbance and vice versa. Second, treating the physical and psychological components independently could result in dangerous drug interactions, if prescriptions are given. Third, if the relation between these two variables is not understood, psychological disorder(s) co-occurring with physical illness frequently go undetected, with possible psychological symptoms being attributed to the physical illness (Katon, 1984). Fourth, utilization of health care services may increase if concurrent physical and psychological disorders are present (Browne et al., 1990; Hawley & Wolfe, 1988). Fifth, the disability and illness severity induced by a physical condition may be worsened by the presence of psychological distress (Nielson & Williams, 1980; Palinkas et al., 1990; Wells, Golding, & Burnam, 1988). Finally, depressive symptoms may increase the risk of non-compliance to treatment for the physical illness (Palinkas et. al., 1990).

Difficulties in Assessing the Temporal Nature of the Relationship Between Illness and Depression

Despite overwhelming evidence for the positive relationship between depression/psychological distress and illness, the temporal relationship between these two variables remains unclear. Unfortunately there are numerous methodological problems in existing research. Some of the weaknesses include the following: 1) the inability to define temporal relationships through cross-sectional research, 2) observations being based on self-report measures that may be unreliable or subject to bias, 3) confounds due to duration of illness, 4) inadequate description of the severity of

depressive symptoms, 5) measurement instruments for depression that include physiologic symptoms which overlap with illness and which have not been standardized on medical populations, and 6) the absence of appropriate controls (Frerichs et. al., 1982; Kathol & Petty, 1981; Rodin & Voshart, 1986, Wells et. al., 1988).

Consequently, attempts to elucidate a causal pathway between illness and depression have proven to be challenging. Many claim that depression is a somatopsychic disorder, i.e. illness leads to depression (Lipowski, 1975), whereas others claim the opposite, that depression is a psychophysiologic illness (Rahe et al., 1964), in which depression results in physical illness. Some research, however, has refuted the latter argument (Grant et al., 1987). Still others believe that there is a common causal factor that results in concurrent depression and illness (Katon, 1984; Hurrelmann, 1989).

In a longitudinal study, Aneshensel, Frerichs, and Huba (1984) attempted to clarify the relationship between depression and physical illness by assessing a causal model of that relationship. Their results supported a positive feedback cycle in which illness initially leads to an immediate increase in depression. Sustained illness and elevated levels of depression both increase the risk for further depression, and high levels of depression magnify the illness. What this study clearly demonstrates is that the relationship that exists between physical illness and depression is a complex and reciprocal one.

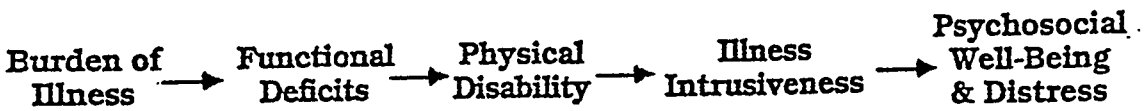
The Path from Illness to Depression

Efforts to understand the association between psychological factors and physical illness have led researchers to propose a wide variety of explanatory pathway models. Having demonstrated that illness and depression are related, the next challenge is to understand more

selectively the mechanism responsible for inducing depression in persons affected by a chronic illness. To elaborate the path by which illness leads to depression, some have proposed that illness acts through indirect, non-physiological routes to induce depression. Chronic illnesses are known to generate numerous additional stressors beyond the medical management of the condition. Non-medical features of illness can impact on a patient's life, potentially increasing the risk of psychological distress. Some of these features include the long-term nature of chronic illness and the associated uncertainty, the proportionately greater efforts at palliation that are required and the disproportionate intrusiveness of chronic conditions compared to more acute illnesses, and the expenses and requirements for numerous ancillary services that accompany chronic illness (Blazer & Williams, 1980; Strauss et. al., 1984). To this list, Rodin and Voshart (1986) add such factors as negative body image, loss of self-esteem, and disrupted work schedule. Impairment or tension in interpersonal relationships is also considered an important illness-induced risk factor for psychological distress (Blazer & Williams, 1980; Rodin & Voshart, 1984).

One interesting model (Fig. 1) that has recently been proposed to explain the impact of illness and its relation to depression, hypothesizes that depression and emotional distress are affected by disease-related and psychosocial variables (Devins et al., 1987, 1992). A similar model to this one has been proposed by others (Wolfe et al., 1988). One factor unique to the model of Devins et al. (1987, 1992) that is derived from illness-produced disruptions/stresses and that is believed to contribute to the psychosocial impact of chronic illness is "illness intrusiveness"; the extent to which an illness and its associated treatment(s) interfere with the performance of normal activities. Illness intrusiveness is believed to mediate the

Figure 2. Proposed model of the psychosocial impact of chronic disabling conditions*.



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relationship between the physical disability and indicators of psychosocial well-being/distress such as depression. A mediator, such as illness intrusiveness, can be thought of as a mechanism through which an independent variable, such as disability, is able to impact upon a dependent variable i.e. depression (Baron & Kenny, 1986).

Rheumatoid Arthritis: A Specific Chronic Condition

Chronic illness and its association with depression is an increasingly important research area. For practical purposes though, it is not always useful to consider all chronic conditions collectively. The focus to this point has been on the relationship between depression and physical illness in general. However, this relationship appears to differ depending on the disease being considered (Palinkas et al., 1990). Therefore, the illness-depression relationship has also been investigated within the context of specific illnesses. One chronic condition in which there has been substantial research on the relation between depression and illness is rheumatoid arthritis.

Rheumatoid arthritis (RA) is a chronic inflammatory disorder that primarily affects the joints and results in pain, swelling, inflammation in and around the joints, and damage to the cartilage and surrounding bone. The onset of RA can be sudden, but more frequently develops insidiously. Characterized by spontaneous exacerbations and remissions, disease activity is often unpredictable. Initial clinical manifestations are usually non-specific and include symptoms such as fatigue, persistent low-grade fever, weight loss, and general malaise. Specific localized articular symptoms develop later, and are typically bilateral and symmetrical. Weakness and increased fatigability are common, but pain is the dominant symptom. As well, affected joints stiffen, especially after inactivity, and joint functioning is decreased (Professional Guide to Diseases, 1992).

RA has a worldwide prevalence of about 1% and an annual incidence of 3/10,000 (Spector, 1990). Although the age of onset is typically between 25 and 50, RA can occur in any age group. As well, RA affects women 3 times as frequently as men. The cause of RA is unknown, however, factors thought to play a role in its etiology include genetic, environmental (nutritional), endocrine factors, and infectious agents (Anderson et al., 1985; Hochberg & Spector, 1990; Spector, 1990).

Psychological Factors in the Etiology of RA

Although not as widely accepted, psychological factors have also been postulated to play an etiological role in the development of RA. In particular, some researchers have suggested that the presence of an "arthritic personality" may predispose a person to RA. Summarizing the views of various proponents of the arthritic personality, Spergel, Ehrlich, & Glass (1978) present the personality pattern as one characterized by self-punitive tendencies, repressed hostility, and problematic interpersonal relationships. Although there is some support for this hypothesis (McFarlane & Brooks, 1988) many have acknowledged that negative personality characteristics are at least equally, if not more likely, to be effects rather than causes of RA (Anderson et. al., 1985; Baum, 1982; Polley, Swenson, & Steinhilber, 1970; Moos, 1964; Robinson et al., 1972; Spergel et al., 1978; Ward, 1971).

In addition, there have been occasional studies that have attempted to show that mood plays a causal role in RA. Moldofsky and Chester (1970) found that negative mood either preceded or occurred simultaneously with increases in subjective and objective measures of joint pain in RA patients. Other research, however, disputes these findings. Bishop et. al. (1987) found the opposite, that fluctuations in depression were associated with major events related to

the illness, such as flare-ups. Although these studies substantiate the presence of a relationship between disease activity and psychological state, they do not prove causality.

The Role of Stress in RA

Others propose that emotional stress and significant life events occurring prior to the onset of RA precipitate the disease process (Baker, 1982; Baker & Brewerton, 1981; Moos, 1964). Although such factors have occasionally been hypothesized to affect those with physical and genetic predispositions by altering immune reactions (Baker, 1982), Anderson et al. (1985) note that studies investigating the relation between pre-existing stress and RA almost never specify how the stress induces the effect. Furthermore, these studies have been plagued with methodological difficulties including retrospective and correlational procedures, and a lack of experimental controls. In addition, differences in the definition of stress among the various studies has complicated attempts to clarify the causal role of stress in RA (Anderson et al., 1985; Moos, 1964).

That additional stressors occur as a consequence of illness is less debated than the notion that pre-existing stress induces illness, especially in the case of RA. Illness-induced burdens that are particularly relevant for RA patients include physical disability, reduced strength and stamina, pain, variable and unpredictable progression of illness and unknown end-point, dependencies on health care professionals, and complex medical regimens (Devins et al., 1992). Other stressors that have been postulated to result from RA include economic burden (Anderson et al., 1985; Devins et. al., 1992; Murphy, Creed, & Jayson, 1988), relationship difficulties (Medsger & Robinson, 1972; Murphy, Creed, & Jayson, 1988), the loss of capacity to care for

oneself (Blazer & Williams, 1980), and the prospect of mortality (Palinkas et al., 1990).

Although some authors have suggested that objective measures of the quality of the life situation (eg. stresses that result from illness) actually bear small relation to a patient's psychological well-being (Cassileth et al., 1984; Hinkle, 1961), most believe that these additional burdens impact negatively on the patient. With the latter view in mind, and considering the variety of stresses induced by chronic illness, it is no surprise that many people with RA experience significant levels of depression and depressive symptoms (Anderson et al., 1985; Baum, 1982; Earle et al., 1979; Frank et al., 1988; Murphy, Creed, & Jayson, 1988; Rimón, 1974; Palinkas et al., 1990; Rimón & Laakso, 1984; Zaphiropoulos & Burry, 1974).

Levels of Depression Among RA Patients

The incidence of depressive reactions during the course of RA is believed to be in the range of 22-80% (Rimón & Laakso, 1984). The proportion of RA patients suffering from depression is elevated in comparison to the rates found in typical community samples (Anderson, et. al, 1985; Frank et. al., 1988; Polley et al., 1970; Weissman & Myers, 1978). However, levels of depression in RA are generally thought to be lower than those in psychiatric populations (Cassileth et al., 1984), and with few exceptions (Cassileth et al., 1984), are believed to be similar to, or higher than those in patients of other chronic conditions (Bishop et al., 1987; Frank et al., 1988; Hawley & Wolfe, 1988; Liang et. al., 1984; Murphy, Creed, & Jayson, 1988; Polley et. al., 1970; Zaphiropoulos & Burry, 1974).

The assumption in many of the studies demonstrating a positive association between depression and RA is that such an association provides support for the idea that the depression is a consequence of the illness or the burdens

resulting from it. Furthermore, correlations with pain and severity, as well as frequent assessments of the degree of depression in RA as mild to moderate (Devins et al., 1992; Bishop, et al., 1987; Rimón, 1974; Hawley & Wolfe, 1988), also provide support for the idea that depression is a reaction to the RA rather than a cause (Murphy et al., 1988; Spergel et al., 1978). Despite the evidence being correlational, severe levels of depression are assumed to be necessary to actually induce illness, whereas milder depressive symptoms are more likely to be a result of the illness.

The Path from RA to Depression

Recently, the viability of the model proposed by Devins et al. (1987, 1992), in which depression among the chronically ill is hypothesized to derive from intrusiveness and disability, was extended to rheumatoid arthritis (Devins et al., 1992). In support of the model, increased illness intrusiveness was significantly associated with increased levels of depressive symptoms. That increased lifestyle disruptions and greater interference with involvement in valued interests and activities (i.e. increased illness intrusiveness) mediated the disability-depression relationship is consistent with research cited earlier.

Others, however, have suggested that the relationship between disability and depression might be mediated by a person's perceptions of illness (Peck et al., 1989). There has been much support for the idea that cognitive factors play an important role in the development of depression (Beck, 1963, 1964). The importance of cognitive factors in the development of depression among physically ill in general (Hinkle, 1961), and among rheumatoid arthritis patients specifically (Smith et al., 1988), has also been established. One measure of illness perceptions that might mediate the disability-depression relationship is the perceived severity of the illness. The association between

objective severity and psychological distress among chronic illness patients has been extensively studied (see Cassileth et al., 1984 for additional references), however objective and subjective measures of a construct are not necessarily equivalent (Devins et al., 1983). The relevance of perceptions of severity to the understanding of reactions to illness has previously been discussed (Devins et al., manuscript submitted; Jenkins, 1966; Klohn & Rogers, 1991; Marteau & Johnston, 1985). Support has been found both for a relationship between perceptions of severity and negative psychological reactions (Murphy et al., 1988; Prohaska et al., 1987), and for the moderating capability of perceptions of severity (Felton & Revenson, 1987). Whereas there is substantial support from research in End-Stage Renal Disease and multiple sclerosis for the relationship between illness intrusiveness and depression (Devins et al., 1983; Devins, Mandin, et al., 1990; Devins, Seland, et al., 1991), less is known about the capacity of perceptions of severity to mediate or moderate the relationship between illness-induced disability and depression.

While testing the viability of the model in which depression is hypothesized to derive from intrusiveness and disability, Devins et al. (1992) found, as previously mentioned, that increased illness intrusiveness was significantly associated with increased levels of depressive symptoms. However, this result was qualified by the presence of an age by intrusiveness interaction. Although age and depressive symptoms were not significantly correlated, it was found that as intrusiveness increased, the severity of depressive symptoms increased significantly more rapidly for comparatively younger than for older individuals. Thus, age was found to moderate the intrusiveness-depression relationship. Moderation is said to occur when the causal relation between two variables changes as a function of the moderator variable (Baron &

Kenny, 1986).

Several potential explanations for this interaction were proposed (Devins et al., 1992; Devins et al., in progress). First, older adults generally have longer durations of illness and thus may habituate to the intrusiveness of their illness. This explanation, however, seems unlikely because duration of illness was not correlated with either intrusiveness, or depression in the study by Devins et al. (1992).

Second, the negative effects of illness-imposed losses among older people may be moderated by normative aging processes. One such process is disengagement, in which, with increasing age, a person becomes psychologically detached from formerly important aspects of life, thus mitigating the impact of intrusiveness. The theory of disengagement, however, has not been widely supported in the normative aging literature (Burrus-Bammel & Bammel, 1985).

The third explanation involves the perceived appropriateness of the timing of illness onset in the lifespan. If arthritis is believed to affect older people, then its occurrence in a younger person may be interpreted as being an inappropriately early event, thereby exacerbating the intrusiveness of the illness.

Relevance of Normative Aging Theory

This latter explanation is based on a theory of normative aging developed by Neugarten (1970, 1979). She proposed that individuals develop expectations about the timing of events in the life cycle which lead a person to anticipate that certain life events will occur at certain ages. Events are judged to be "on-time" or "off-time" (i.e. age-appropriate or age-inappropriate) on the basis of these expectations.

From this perspective, normal/expectable life events are not crises per se, but rather become so when they occur

"off-time". Hence, events occurring at points in the life cycle that are believed to be inappropriately early are likely to be traumatic for the individual if one expects that s/he should not have to endure them until a later stage of life. For example, 70% of people who retired as planned were content in retirement, compared to 20% who retired unexpectedly (Barfield & Morgan, 1970). Baler and Golde (1964) found that younger widows were at greater risk for both mental and physical illness than were older widows, presumably because widowhood is not expected until later in life.

Extending Neugarten's theory to the interaction observed by Devins et. al. (1992), it may be that the occurrence of RA among the comparatively young patients was perceived to be "off-time." Rheumatoid arthritis may have been identified with other arthritic conditions, such as osteoarthritis, that actually do occur among comparatively older people. Thus, although RA can and does occur across the life span, it may be an expected event among the elderly, whereas its onset in comparatively young people may be perceived to be an off-time event. This, in turn, may exacerbate the deleterious psychosocial impact of illness intrusiveness. As a result, increasing levels of intrusiveness may produce greater distress among comparatively young people.

Illness Expectations

Neugarten's theory is based on the fact that people develop expectations about events in the life cycle. Extension of this theory to the interaction of interest implies that people have expectancies that relate directly to illness. Research on the schematization of illness has shown that people do indeed develop expectations about the nature of illness (Lau & Hartman, 1983; Lau, Bernard, & Hartman, 1989; Leventhal, 1984; Meyer, Leventhal, & Gutmann,

1985; Turk, Rudy, & Salovey, 1986). This research has identified several components that people typically use to represent illness, including identity, consequences, time line, cause, and cure (Lau et al., 1989). Expectations about the appropriateness of timing of an illness in the life cycle could potentially fit with the components of time line and/or cause. The time line component has been defined as the temporal course of the disease, and represents beliefs about the course of the illness, how long it will last, whether it is acute or chronic (Lau & Hartman, 1983; Lau, Bernard, & Hartman, 1989). The cause component entails beliefs about the factors that lead to disease onset, and can include beliefs about whether an illness is "aging-related" (Lau, Bernard, & Hartman, 1989; Leventhal, 1984). In any case, there is evidence that people do possess expectations about illness, including the timing of illness occurrence(s) in the life-cycle.

Perceptions of Appropriate Timing of Illness

Although the prevalence of chronic illness among younger age groups is increasing, the fact remains that physical illnesses, particularly chronic ones, are still most prevalent among the elderly (Ban, 1984; Costa & McCrae, 1980; Langner, 1963; Neff, et. al., 1980; Schwab et.al, 1978; Westbrook & Viney, 1983). Over 80% of elderly subjects have been reported to have at least one chronic medical condition (LaRue et. al, 1979; Westbrook & Viney, 1983). In fact, Andrews et al. (1978) found that age was the best single predictor of physical health among adults. Jylha et al. (1986) found self-rated health was explained by number of chronic conditions, particularly among those aged 70-75. Because of the high prevalence of chronic illness among older people, it is reasonable to hypothesize that such illness might be an expected event. If it is an expected event among this older age group, illness may be

more likely to be perceived as on-time among the elderly.

There has been some support for the idea that illness is indeed an expected event in old age. Westbrook and Viney (1983) have suggested that the frequency of chronic illness among the elderly affects the perceptions of, and reactions to illness among this age group. That health expectations decline with age has also been speculated by Costa and McCrae (1980). Evidence of such declines in health expectations can be construed as support for the idea that illness is an anticipated event in older age. In 1975, Tornstam found that with advancing age, aspiration levels for health declined. He asserts that lower aspiration levels permit the elderly to feel content with poorer health. Cockerham et al. (1983) also support the idea that the level of health in old age is expected to decline by suggesting that it is easier for elderly [than for younger] people to perceive their health as good enough to meet the needs of their environment. Even normal age-related changes in body image such as stooped posture, diminished muscle mass, and loss of teeth can contribute to negative perceptions of aging (Ouslander, 1982). Not surprisingly, Rodin (1980) notes that health problems among the elderly are considered to be natural and inevitable, and Siegler (1989) points out that people often fail to differentiate the effects of normal aging from symptoms of disease. The belief that aging is invariably associated with illness has been suggested to lead to the normalization of symptoms, and is the most frequent explanation for overly positive health assessments among the elderly (Levkoff et al., 1987). Thus, illness appears to be an accepted and expected event in old age.

Differences in Perceptions of Timing of Illness

Although the perception may generally be that illness is expected among older people, this belief may vary

depending on the particular condition being considered, with some illnesses perceived as diseases of aging, and others as childhood illnesses. In reality, some conditions occur only among children (eg. muscular dystrophy) and can truly be called childhood diseases, whereas others are only known to occur among the elderly and so are diseases of aging (eg. Alzheimer's disease). Many conditions, however, can occur across the lifespan and do not fit neatly into either category. Actual timing (as determined by possible age of onset) may not coincide with the perceptions of the general public though. For example, Leventhal (1984) claims that arthritis is a "disease of aging" although RA actually occurs across all ages. Inaccuracy on the part of the public is corroborated by pilot research which has shown that illness knowledge among a large undergraduate population is poor (Saary et al., 1993). Therefore, an assessment of the degree of correspondence between actual and perceived timing is necessary to assess whether an illness is "on-time" or "off-time".

The belief that illness is expected among older people may also vary as a function of age. Leventhal (1984) found age differences in the perception that certain diseases are caused by getting old (older respondents saw some illnesses as less related to aging than younger subjects did). Research assessing people's illness cognitions does not appear to have included evaluations of the appropriateness of the timing of the illness.

Age Differences in Emotional Reaction to Illness

Some research exists that confirms differential emotional reactions to the same illness at various ages (i.e. main effects of age). For example, Leventhal (1984) found age-dependent changes in emotions associated with illness: as age increased, responses of anger, fear, and shame resulting from illness decreased. She proposed that

older people are more willing to accept disease. Mages and Mendelsohn (1979) reported that older cancer patients experienced less anger than younger patients. Westbrook and Viney (1983) also found age-related differences in emotional reaction to illness, with older people exhibiting a pattern of acceptance or resignation and experiencing less anxiety than younger or middle-aged groups. They claim that reactions to illness are related to a person's stage in the life cycle.

Besides Devins et. al. (1992), others have acknowledged that Neugarten's proposal may account for observed age differences in responses to various life stressors including chronic illness (Felton & Revenson, 1987; Mages & Mendelsohn, 1979; Lazarus & DeLongis, 1983). However, the explanation that timing perceptions are responsible for the differential impact of illness at various ages has not yet been tested directly, and has only been speculated as an explanation for age main effects, not interactions, in previous research.

Purpose and Rationale

This study and the hypotheses and analyses that comprise it, can essentially be considered in terms of three main goals. The first objective was to replicate the work of Devins et al. (1992) by reproducing the age by intrusiveness interaction and verifying the validity of the proposed model of psychosocial impact of chronic illness. The second objective was to assess the possibility that perceptions of severity could mediate or moderate the relationships among disability, intrusiveness, and depression. The third objective was to evaluate normative aging hypotheses in the context of the illness RA by evaluating perceptions of the appropriate timing of rheumatoid arthritis in the lifespan, and age differences in such perceptions, and determining whether Neugarten's theory

is useful in explaining the age by intrusiveness interaction.

Several specific hypotheses were tested, based on these purposes. The first hypothesis was that depressive symptomatology among RA patients increases with intrusiveness, but such increases would be more pronounced among younger than among older patients (i.e. there is an age by intrusiveness interaction).

The second hypothesis was that the results of this study would support to the model proposed by Devins et al. (1987, 1992) in which disability leads to depression indirectly through a mediator called intrusiveness.

The third hypothesis was that the relationship between disability and depression would also vary depending on the perceived severity of RA. The tests of the second and third hypotheses were based on regression analyses of the relevant variables as described in detail by Baron and Kenny (1986). Initially though, the independence of perceptions of severity from both disability and intrusiveness scores was evaluated using partial correlations.

Because both mediators and moderators have been shown to affect the illness-depression relationship, it was also hypothesized that in the event that perceptions of severity do not mediate the relationship between disability and depression, such perceptions could still be important as moderators. There are several possible relationships that could be moderated by perceptions of severity, including the disability-intrusiveness relationship, the intrusiveness-depression relationship, and the disability-depression relationship. Because there were no a priori reasons for suspecting that perceptions of severity would be more likely to moderate one than the other(s) of these relationship, all three were tested.

The remaining hypotheses relate to the timing of RA. They include the hypothesis that RA is perceived as a

disease of aging, that RA is off-time most frequently among younger, rather than older patients, and that those experiencing an off-time event will be more distressed, particularly at higher levels of intrusiveness.

Importance of This Research

This research is theoretically important for several reasons. First, the age by intrusiveness interaction found by Devins et al. (1992) is unique, so replication would serve to verify the legitimacy of this phenomenon. Second, although much research has substantiated the existence of age differences in reactions to chronic illnesses, an empirical test of Neugarten's theory as an explanation for these differences has yet to be documented. Therefore this research provides a preliminary assessment of the usefulness of a normative aging theory in explaining depressive reactions to chronic illness, particularly RA. Finally, on a very general level, a test of this hypothesis would integrate the normative aging and health psychology literatures.

This research also has applied value. The impact of illness is known to extend beyond the physical domain, however, the association between physical illnesses like RA and psychological reactions such as depression is complicated by a variety of modifying/mediating factors. Considering that health entails "complete physical, psychological, and social well-being" (WHO, 1958), the need for integration in the provision of complete and effective health care is obvious. Thus, if the most effective treatment of disease requires attention to non-physical components of health, it is a worthy endeavour to develop a more holistic understanding of the consequences of illness, taking into consideration the physical, psychological, and social repercussions, as well their interactions with each other.

METHODS

Subjects

A sample of 65 rheumatoid arthritis patients was obtained through the University of Calgary Heritage Medical Research Clinic. The number of subjects included in this study was derived from a power analysis for partial correlation and regression coefficients (available from Devins et al., 1992), and was the number required to obtain a power level of .80 (Cohen & Cohen, 1983). The sample size of 65 represents a response rate of 43%.

Patients were invited to participate only if they had not already been involved in similar recent research, and if they had greater than 80% diagnostic certainty of RA based on standard clinical criteria as determined by a rheumatologist. Other inclusion criteria included approval of participation by both the specialist and the referring physician, and ability to speak English. Bedridden patients, however, were not contacted.

There were 46 (70.8%) female and 19 (29.2%) male participants who ranged in age from 21 to 84 years, with a mean of 53.3 years. The average duration of RA in this sample was 12.8 years (sd = 15.2). A summary of demographic characteristics can be found in Table 1.

Procedure

A series of self-administered questionnaires (described in detail below), as well as one page of demographic questions, were compiled into a booklet and subjects completed them in the context of an evening seminar about RA held at the Foothills Hospital. Of the 65 subjects in this study, 44 (68%) attended the seminar. For the remaining 21 (32%) subjects who were interested in participating but who were unable to attend the seminar, the questionnaires were completed during a follow-up home visit. Although no demographic differences were expected between the subjects

completing the questionnaires at home versus those completing them at the seminar, t-tests were performed on demographic and criterion variables to verify this assumption. No significant differences between the groups were found, so the data were collapsed and treated as a single group.

Measures

The instruments used in this study are included in the Appendix, and include the Intrusiveness Ratings Scale, the Center for Epidemiologic Studies Depression Scale, and the Stanford Health Assessment Questionnaire. Perceptions about illness were assessed via several Likert rating scales.

Intrusiveness Ratings Scale

Illness intrusiveness, defined as the extent to which an illness and its associated treatment(s) interfere with the performance of normal activities, was assessed using the Intrusiveness Ratings Scale. This scale was first developed by Devins et al. (1983) to investigate the hypothesis that intrusiveness contributes to the emotional impact of End-Stage Renal Disease (ESRD). Since then, the scale has been used extensively in ESRD research (Binik et al., 1990; Devins et al., 1986; Devins, Armstrong et al., 1990; Devins, Mandin et al., 1990; Devins, Mann et al., 1990), and has been adapted for use in various chronic conditions, including multiple sclerosis (Devins et al., 1993), and rheumatoid arthritis (Devins et al., 1992), among others.

Psychometric properties of the Intrusiveness Ratings Scale for use in ESRD populations have been established (Binik et al., 1990; Devins et al., 1983; Devins, Mandin et al., 1990). These authors report adequate reliability and validity. For example, test-retest reliability has been reported to be .79, and internal consistency coefficients have been repeatedly high (>.80). Construct validity has

been supported by the facts that perceived intrusiveness differs between dialysis and post-transplant patients and that it is related to positive and negative affect among ESRD patients. Also, self-ratings of perceived intrusiveness have been corroborated by ratings obtained from treatment staff and significant others. The validity of this scale was also verified in an RA population by Devins et al. (1992) by significant correlations between intrusiveness and indices of physical disability.

Center for Epidemiologic Studies Depression Scale: (CES-D)

The CES-D scale was used to assess depressive symptomatology. It is a self-report scale designed specifically for use in research with the general population. The CES-D has excellent psychometric properties (Radloff, 1977; also see Blalock et al., 1989, and Weissman et al., 1977). Its minimal emphasis on the somatic symptoms of depression makes it especially practical for use with medical patients for whom disease symptoms and vegetative symptoms of depression may be confounded (Devins & Orme, 1985; Devins, Orme, Costello et al., 1988).

To correct the problem of somatic contamination, adjusted scores, calculated by removing the somatically contaminated items are frequently used (Callahan et al., 1991; Frerichs et al., 1989) but have been found to have no significant effect on the outcome of studies based on the covariation of depression with other variables (Blalock et al., 1989). In fact, agreement between total and adjusted CES-D scores is not unusual (Devins et al., 1992; Frerichs et al., 1977). Moreover, because the original version of the CES-D was found to have greater reliability, Blalock et al. (1989) suggest that the original is actually preferable to the adjusted version. Both total and CES-D adjusted scores were calculated in this study as a conservative precaution (adjustment was based on the method used by

Devins et al., 1992). Because all analyses were comparable regardless of whether the total or adjusted score was used, all further references to depressive scores are based on the total rather than the adjusted CES-D score.

Stanford Health Assessment Questionnaire: (HAQ)

The Stanford Health Assessment Questionnaire is an instrument that was designed specifically for use in arthritic populations, and which assesses patient outcome on five dimensions: death, disability, discomfort, drug or therapeutic toxicity, and dollar cost, each of which are further divided into subdimensions, and again into components (Fries et al., 1980). In this study, subjects completed only the physical disability and pain (a discomfort subdimension) scales of the HAQ. The functional disability index was used as a measure of arthritis-induced disability. The HAQ disability scale assesses those aspects of disability that are least likely to be influenced by psychological factors (Smith, et al., 1988; Thompson, 1988).

The measurement properties of this disability assessment instrument are respectable (Fries et al., 1980; Fries et al., 1982; Fries, 1991; Peck et al., 1989). Test-retest reliability is .86 (Fries et al., 1980), and the results correlate highly ($r = .91$) with other measures of disability in RA such as the AIMS (Arthritis Impact Measurement Scales; Fries, Spitz & Young, 1982). Extensive validation is one of the benefits of using the HAQ, as is ease of administration (Patrick & Deyo, 1989).

Perceptions of Illness

In addition to assessing the unique situation of each of the subjects, beliefs about illness were assessed in a more general sense. Subjects were asked to rate each of 5 conditions, including arthritis, in terms of its intrusiveness and severity, as well as to identify the life

stage with which each condition was most associated. Both intrusiveness and severity were assessed using 7-point Likert scales consistent with those used on the Intrusiveness Ratings Scale (see Appendix).

To identify which life stage was most appropriate for each condition, the lifespan was divided into four age groups. In the literature there is no standard age range associated with each of the groups of interest (cf. Leventhal, 1984; Mages & Mendelsohn, 1979; Westbrook & Viney, 1983) so the age groups were divided as follows: Children and Adolescents (0-17), and Young (18-34), Middle (35-64), and Old (65+) adults.

Analyses

Preliminary Analyses

Some researchers have suggested that depressive symptomatology among RA patients might be affected by demographic variables (Earle et al., 1979; Hawley & Wolfe, 1988). On the contrary, others have found no relationship between depression and demographic variables among medically ill patients including those with RA (Moldofsky & Chester, 1970; Rodin & Voshart, 1986; Zaphiropoulos & Burry, 1974). In this study, relationships between demographic variables and depressive symptomatology were examined to identify any potential additional covariates besides HAQ disability scores. Further descriptive statistics and correlational analyses were calculated to provide statistics for comparison to others studies.

Replication

A two-way analysis of partial variance was the method used to test the relationship between age, intrusiveness, and depressive symptomatology above and beyond any shared effects with disability. This method is a special case of

hierarchical multiple regression in which covariates are entered as a block first, and the independent variable is entered last (Cohen & Cohen, 1983).

Mediator/Moderator Relationships

Validating the Model.

Regression analyses were used to test whether the results of this study support the model proposed by Devins et al. (1987, 1992). In that model, it was hypothesized that disability (the independent/predictor variable) leads to depression (the criterion/dependent variable) through the intermediate variable of intrusiveness (the mediator). According to Baron and Kenny (1986), four conditions must be met to establish mediation. First, when the mediator is regressed on the independent variable (iv), the iv must be shown to affect the mediator. Second, when the dependent variable (dv) is regressed on the iv, the iv must be shown to affect the dv. Third and fourth, when the dv is regressed on both the iv and the mediator, the mediator must affect the dv, and the effect of the iv on the mediator must be less than it was in the second regression.

Mediational testing can also be accomplished using strictly correlational analyses, however it is preferable to measure the effect of the iv on the dv using regression rather than correlation coefficients, because regression coefficients are less affected by possible measurement error in the dv.

Perceptions of Severity as a Mediator.

The hypothesis that perceptions of severity mediate the relationship between disability and depression, was tested using the same regression strategy described above.

Perceptions of Severity as a Moderator.

In a model which includes the variables of disability, intrusiveness, and depression, there are three potential bivariate relationships that could be moderated by perceptions of severity: (1) the disability - depression relationship, (2) the intrusiveness - depression relationship, and (3) the disability - intrusiveness relationship. Each of these possible moderator relationships was tested using separate regression analyses in which the main effects of the iv and moderator were first entered simultaneously, and the interaction of the proposed moderator and the independent variable was entered last. The hypothesis that a variable (such as perceptions of severity) serves as a moderator would be supported by a significant interaction between the proposed moderator and the predictor (Baron & Kenny, 1986).

Timing

A frequency analysis was performed to determine whether RA was perceived to be an illness of aging as expected. A oneway ANOVA was computed to assess whether there were age differences in perceptions of the age most associated with RA. Furthermore, the assumption that those experiencing an off-time illness would be primarily young adults was verified.

Two timing variables were calculated based on information provided in the questionnaires and demographics sections. Patients' beliefs about which life stage was most associated with arthritis was compared both with their present age (T1), and with their age at onset of RA (T2). In patients for whom there was congruence between the age believed most appropriate for arthritis and either actual age or age at onset, the illness was said to be on-time, whereas lack of congruence indicated that the illness was off-time. Thus, two separate assessments (timing variables)

of whether a patient's RA was on-time or off-time were made. A value for each timing variable was assigned based on a continuum, depending on whether the actual ages (i.e. present age and age at onset) were less than, equal to, or greater than the age perceived to be "most appropriate" for RA. A categorical score of 1 was given if the actual age was less than age believed appropriate, corresponding to "early off-time" occurrence of RA. If actual age was equal to appropriate age, then a score of 2 was given, indicating "on-time" occurrence of RA. Finally, a score of 3 signified "late off-time" occurrence of RA, and corresponded to actual age being greater than the age believed appropriate for RA.

With the two timing variables representing the grouping variables, separate 2-way (timing x intrusiveness) ANOVAs were performed to determine whether levels of depressive symptomatology differed as a function of the timing of the illness, and whether potential timing - depression relationships would vary depending on the level of intrusiveness.

RESULTS

Demographics

Demographic characteristics of the sample are presented in Table 1. Relationships between demographic variables and depressive symptomatology were examined to identify any potential additional covariates besides HAQ disability scores. Income, years of education, duration, and gender were not related to CES-D scores, and thus were not included as covariates in the analysis of partial variance.

Further correlational analyses were calculated to provide statistics for comparison to others studies, the results of which are presented in Table 2. Intrusiveness was found to be significantly and positively correlated with both disability ($r(65) = .53$, $p < .001$) and depressive symptoms ($r(63) = .58$, $p < .001$). The relationship between disability and depressive symptomatology was also significant ($r(63) = .58$, $p < .001$) in this study. Neither intrusiveness nor depression were related to age, although the correlation between age and disability was significant ($r(63) = .22$, $p < .05$).

Reliability Estimates

Internal consistency was assessed in each of the measurement instruments used. Chronbach's alpha values for the CES-D, HAQ, and Intrusiveness Ratings Scale were .87, .91, and .88 respectively.

Descriptive Statistics

CES-D scores ranged from 1 to 40 out of a maximum of 60, with a mean of 16.5. For this sample of RA patients, intrusiveness ratings ranged from 13 to 78, with a mean of 37.9. The range for HAQ total scores was .10 to 2.8 with a mean of 1.3.

Table 1

Demographic characteristics of the sample

Variable	Descriptive Statistics
Age (M, SD)	53.5, 17.1
Sex (n)	
Male	19 (29.2%)
Female	46 (70.8%)
Marital Status (n)	
Single	4 (6.2%)
Married	48 (73.8%)
Sep/Div/Wid	13 (20.0%)
Employment Status (n)	
Working (full time)	18 (27.7%)
Working (part time)	8 (12.3%)
Retired	23 (35.4%)
Disability Pension	8 (12.3%)
Other (student, homemaker etc.)	8 (12.3%)
Income (K) (M, SD)	27, 8.9
Years of Education (M, SD)	12.3, 3.3
Duration of RA (yrs) (M, SD)	12.8, 15.2

Table 2

Correlations among disability, intrusiveness, depression, and age

Variable	1	2	3	4
1) Disability (HAQ)	1.00			
2) Intrusiveness (IRS)	.53***	1.00		
3) Depression (CES-D)	.58***	.58***	1.00	
4) Age (years)	.22*	-.20	-.04	1.00

*** $p < .001$

* $p < .05$

Replication

A 2-way age by intrusiveness analysis of partial variance was performed, using HAQ disability total scores as a covariate. The summary table of this analysis is presented in Table 3, which indicates that the covariate (HAQ disability) accounted for a significant amount of variance in depressive scores (R^2 = .33, p < .001). Main effects accounted for a significant amount of the variance in depressive scores above that explained by disability (R^2 Change = .11, p < .01). The interaction term did not account for additional variance beyond that already accounted for by the covariate and the main effects. The interaction term was also non-significant when only the main effects and the interaction were included in the model, without the covariate (R^2 Change = .01, p > .05).

Mediator/Moderator Relationships

Validating the Model

The hypothesis that illness intrusiveness mediates the relationship between disability and depression was tested using regression analyses. Table 4 provides a summary of regression coefficients from the three relevant equations and clearly shows that disability affected both intrusiveness and depression, and that intrusiveness affected depression. Thus, the first three criteria for mediation were met. The final criterion, that the effect of disability on depression be less when intrusiveness is held constant, albeit a reduction in the absolute value of b, was not met because the disability coefficient remained significant.

Table 3

Analysis of partial variance summary table relating to the test of age as a moderator of the intrusiveness - depression relationship

Predictor	df	Partial r	R^2 Change
Covariate	1,60		.327***
Disability		.57***	
Main Effects	2,58		.105**
Age		-.05	
Intrus.		.36**	
Interaction	1,57		.009
Age x Intrus.		.13	

*** $p < .001$

** $p < .01$

Table 4

Regression coefficients for evaluating intrusiveness as a mediator of the disability - depression relationship

Eqn	Criterion	Predictor(s)	Regression Coefficient (b)
1	Intrusiveness	Disability	12.13***
2	Depression	Disability	7.58***
3	Depression	Intrusiveness	.22**
		Disability	4.95**

*** $p < .001$

** $p < .01$

Perceptions of Severity as a Mediator

Prior to any analyses using perceptions of severity, the independence of the construct of perceived severity from disability and from intrusiveness was established through partial correlation analyses. Both disability and perceptions of severity were significantly correlated with each other and with depression scores. However, after partialling out the effects of perceptions of severity, the correlation between disability and depression remained highly significant ($r(59) = .48$, $p < .001$). Similarly, intrusiveness and perceptions of severity were correlated with each other and with depression. After controlling for the effects of perceived severity, the relationship between intrusiveness and depression remained significant ($r(59) = .45$, $p < .001$).

The ability of perceptions of severity to mediate the relationship between disability and depression was evaluated. The results of this analysis, which are presented in Table 5, indicate that disability affected both perceptions of severity and depression, and that perceptions of severity affected depression. Similar to the analysis of intrusiveness as a mediator, however, despite a small reduction in the absolute value of the regression coefficient, the relationship between disability and depression remained significant even when perceptions of severity were held constant.

Perceptions of Severity as a Moderator

Potential moderating effects of perceptions of severity were also considered. Three separate regression analyses were conducted to examine the 3 possible relationships that could be moderated by perceptions of severity, the results of which are presented in Tables 6, 7, and 8. Tables 6 and 7 respectively illustrate that perceptions of severity moderated neither the relationship between disability and

Table 5

Regression coefficients for evaluating perceptions of seriousness as a mediator of the disability - depression relationship

Eqn	Criterion	Predictor(s)	Regression Coefficient (b)
1	Seriousness	Disability	.95***
2	Depression	Disability	7.58***
3	Depression	Seriousness	1.28*
		Disability	6.38***

*** $p < .001$

* $p < .05$

Table 6

APV summary table relating to the test of perceptions of seriousness as a moderator of the disability - depression relationship

Predictor	df	Partial r	R^2 Change
Main Effects	2,58		.36***
Disability		.48***	
Perc. Severity		.23	
Interaction	1,57		.03
Dis. x Severity		.20	

*** $p < .001$

Table 7

APV summary table relating to the test of perceptions of seriousness as a moderator of the intrusiveness - depression relationship

Predictor	df	Partial r	R^2 Change
Main Effects	2,58		.34***
Intrusiveness		.45***	
Perc. Severity		.15	
Interaction	1,57		.02
Int. x Severity		-.17	

*** $p < .001$

Table 8

APV summary table relating to the test of perceptions of seriousness as a moderator of the disability - intrusiveness relationship

Predictor	df	Partial r	R^2 Change
Main Effects	2,58		.41***
Disability		.38**	
Perc. Severity		.43***	
Interaction	1,57		.06*
Dis. x Severity		.32*	

*** $p < .001$
** $p < .01$
* $p < .05$

depression, nor between intrusiveness and depression. Table 8 however, shows that a significant interaction between disability and perceptions was found when intrusiveness was the specified criterion variable. This finding is illustrated in Fig. 2 which indicates that the same level of disability resulted in different intrusiveness ratings depending on whether the illness is perceived to be severe or not.

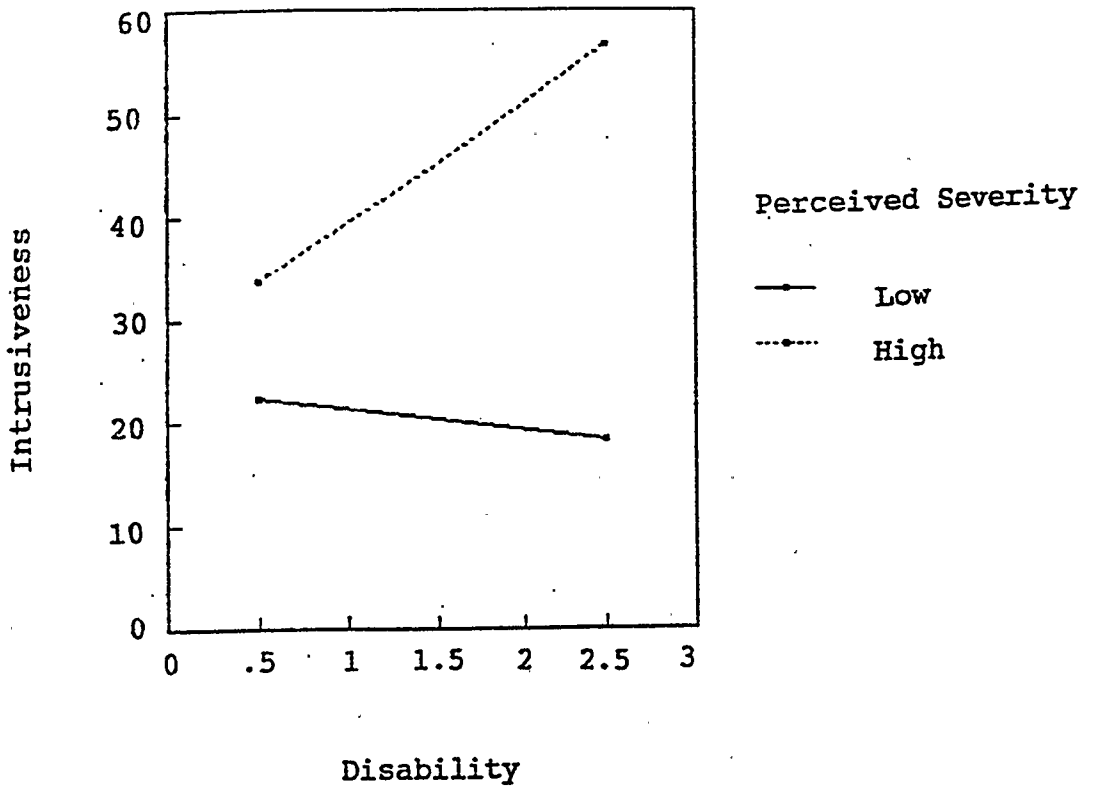
Timing

The first analysis of interest was to determine whether arthritis is perceived as a disease of aging. Results indicate that overall, the majority of subjects (62.7%) believed arthritis to be a condition that affects middle adults (age 35-64), as opposed to older adults (27.1%) as expected.

Age differences in people's beliefs about which life stage was most likely to be associated with arthritis were also assessed. A oneway ANOVA revealed that there were no significant differences between the young, middle, and older subjects' perceptions of the age group most associated with RA ($F(2,60) = .87$, $p > .05$). Although no significant age differences were found, the modal age groups selected as most affected by arthritis among the younger, middle, and older adults in this sample of RA patients were middle, middle, and old respectively.

To determine whether the occurrence of RA was off-time primarily among the younger patients, the frequencies of off-time, early, and late timing occurrences were examined for each of the 3 age groups (18-34, 35-64, 65+) on each of the two timing variables. On T1, (the timing variable based on actual/present age) it was found that younger adult subjects were either early off-time or on-time, compared with those of older adult ages, who were either on-time or late off-time. Those of middle adult age experienced the

Figure 2. Intrusiveness as a function of disability, and perceived severity.



range of timings. For the T2 variable (timing based on age of onset of RA in each subject), among subjects who were either middle or older adults, timing was either early or on-time at the time of onset, however for the younger adults, timing was always early. These results are partially a function of the fact that RA was universally perceived as an illness associated with middle age.

To evaluate whether depression scores were associated with timing, and whether this association varied as a function of intrusiveness, levels of depressive symptomatology for early, on-time and late occurrences of RA were compared at both high and low levels of intrusiveness. Scores of 13 through 51 on the Intrusiveness Ratings Scale were coded as low intrusiveness, whereas scores ranging from 52 to 91 were coded as high intrusiveness. (A score of 52 reflects the midpoint of the possible total intrusiveness scores, which ranged from 13 to 91.) Two separate factorial ANOVAs were computed to assess whether depressive symptoms differed as a function of intrusiveness and timing. The first analysis used T1 (present age) and the second used T2 (age at onset) as the timing variable. Average depression scores for early, on-time and late occurrences were 17.7, 14.6, and 20.7 respectively for T1, and 16.9 and 14.8 for T2 (no late occurrences were reported for T2). However, neither the main effect of timing, nor the interaction of timing with intrusiveness was significant in either of the two analyses. (Consistent with the significant correlations between intrusiveness and depression noted earlier, significant main effects of intrusiveness were found in both analyses.)

DISCUSSION

This study was based on three general goals: 1) replication of past research, 2) assessing the relevance of perceptions of severity to the relationships among disability, intrusiveness, and depression, and 3) evaluation of a normative aging hypothesis. More specifically, the purposes were to replicate the age by intrusiveness interaction found by Devins et al. (1992), to verify the validity of the model of psychosocial impact of chronic illness, to assess the possible mediator and moderator roles of perceptions of severity, to evaluate perceptions of the appropriate timing of rheumatoid arthritis in the lifespan, and to determine whether Neugarten's theory is useful in explaining the age by intrusiveness interaction.

Demographics and Descriptive Statistics

Subjects were comparable to populations of RA patients from other research in terms of the demographic variables listed in Table 1 (Devins et al., 1992; Hawley & Wolfe, 1988; Nicassio et al., 1985; Smith et al., 1988). CES-D scores with a mean of 16.5, indicate that overall, the average level of depressive symptomatology falls within the range (16-20.5) classified as mild depression (Devins & Orme, 1985). These results are consistent with the levels of depressive symptomatology found among RA patients in other research (Devins et al., 1992; Bishop et al., 1987; Blalock et al., 1989).

Replication

Overall, the results of this study did not support the presence of an age by intrusiveness interaction among rheumatoid arthritis patients. Such results are not consistent with those obtained by Devins et al. (1992), nor has the interaction been replicated in multiple sclerosis (MS) or End-Stage Renal Disease (Devins et al., manuscript

submitted). However, there are potential explanations for these seemingly inconsistent findings.

In both this study and that of Devins et al. (1992), the relations of interest were those of age and intrusiveness with depression, beyond any effects that overlapped with disability. Disability is known to correlate with both age (Fries et al., 1982; Fries, 1991; Wolfe et al., 1988) and with intrusiveness (Devins, 1989; Devins et al., 1993; Fries, 1983). Significant correlations of both age and intrusiveness with HAQ were found in this study as well as that of Devins et al. (1992). These results are consistent with the previously mentioned findings. However, in this study, a positive correlation was also found between disability and depressive symptoms. This means that a significant amount of the variance in CES-D scores was accounted for by disability. In contrast, Devins et al. (1992) did not find a significant correlation between disability and depression ($r = .15$, $p < .05$). Perhaps as a consequence of using disability as a covariate, the amount of variance in depressive scores in this study was reduced to such an extent that after removal of the variance associated with the main effects, the interaction term could not account for a significant amount of variance over and above that already explained by the combination of disability and the main effects.

This explanation, however, does not seem to be the most fitting, based on the data. When only the main effects and the interaction were included in the model, without the covariate, the interaction term was also non-significant. Alternatively, it may just be the case that the age by intrusiveness interaction is simply not a reliable phenomenon.

The insignificant correlation between depression and disability found by Devins et al. (1992) appears to be somewhat unusual. In spite of some support for a lack of

relationship between disability and depression (McFarlane & Brooks, 1988; Zaphiropoulos & Burry, 1974), intuitively it seems reasonable that as disability increases, so might depressive symptomatology. In fact, this premise has been widely supported in past research including studies of arthritis populations. The depression subscale scores from the Arthritis Impact Measurement Scales (AIMS) were found to be related to American Rheumatism Association (ARA) functional class (Meehan et al., 1982). Wolfe et al. (1988) found the AIMS depression index to be related to HAQ scores, as did Hawley and Wolfe (1988; $r = .30$). Peck et al. (1989) correlated both BDI (Beck Depression Inventory) and HRSD (Hamilton Rating Scale for Depression) scores with HAQ and found respectively, $r = .37$, $p < .001$, and $r = .24$, $p < .01$.

Peck et al. (1989) raised the issue however, that depression scores in their study were contaminated with somatic items which could magnify the extent of these correlations. Several studies have addressed this issue by deriving adjusted depression scores based on the removal of somatic items from the measurement scale, and then assessing the relation of these adjusted depression scores and disability. Callahan et al. (1991) assessed whether CES-D scores were related to difficulties in performing activities of daily living, which are believed to assess disability because of high correlations with other measures of functional status. Correlation coefficients of $r = .37$, $p < .01$ and $r = .35$, $p < .05$ were found for unadjusted and non-RA-related CES-D scores (with ADL scores) respectively. Blalock et al. (1989) correlated CES-D scores with lower extremity function on the AIMS and found that in 2 different studies from which they were reanalysing data, correlations between disability and original CES-D scores were $r = .32$, $p < .01$, and $r = .50$, $p < .0001$, and with adjusted CES-D scores correlations were $r = .29$, $p < .05$, and $r = .43$, $p < .05$ respectively. Incidentally, Fries et al. (1982) and

Brown et al. (1984) verified that the AIMS and HAQ instruments both measure the same disability construct, with results from both measures being highly correlated (r = .91).

Measures of disability have also been shown to be significantly related to psychosocial well-being (assessed via the CES-D and other measures) in conditions other than RA, including multiple sclerosis (Devins, Seland, et al., 1993). Also, in a comparison of six diagnostic groups, Cassileth et al. (1984) found a direct relation between declining physical status and mental health scores. Although it seems that estimates of the size of the correlation between disability and depression depend on the measurement scale used, the literature nonetheless seems to support a significant relationship between measures of depression and disability in RA, as was found in the present study.

Some might argue that a positive correlation between depression and disability scores only indicates that the same construct is being measured by both. Peck et al. (1989) hypothesized that patients' reports of limited functioning could indicate a depressive outlook rather than actual functional impairment. They assessed whether self-reported functional status actually reflects level of disability rather than just emotional adjustment, and concluded that results from the HAQ can safely be interpreted as a measure of disability not as a measure of emotional status. The independence of these two constructs (disability and psychological status/depression) has also been verified elsewhere (Blalock et al., 1989; Brown et al. 1984; Callahan et al., 1991).

Interestingly, Devins et al. (1992) themselves present a provisional model of the psychosocial impact of chronic conditions which describes the existence of a relationship between disability and depression. Unlike much other

research though, they do not assume the relationship to be a direct one. Instead, and similar to the ideas of Peck et al. (1989), they offer a model in which disability leads to depression through a mediator. This mediating factor is called illness intrusiveness.

Illness intrusiveness is a construct that is defined in terms of the extent to which illness-induced lifestyle disruptions prevent continued involvement in valued activities and interests (Devins et al., 1983, 1992). Illness intrusiveness is thought to impact negatively on psychosocial well-being (eg. increase depressive symptomatology) by both reducing the availability of rewarding experiences and by reducing personal control in important domains of life (Devins et al., 1993). Physical disability, defined as limitations to the performance of complex functions, is believed to be one of the disease characteristics from which illness intrusiveness is derived (Devins et al., 1992, 1993). Thus, physical disability makes it more difficult to continue participating in valued activities and interests. Inability to maintain involvement in such activities reduces the availability of rewarding experiences and reduces personal control, generating negative psychosocial reactions (such as depression) to the illness.

Mediator/Moderator Relationships

Validating the Model

This model predicts that the effect of disability does not have a direct effect on depression, but rather occurs indirectly through intrusiveness. If this is the case, the pattern of regression coefficients should reflect those expected in such a model. This pattern would entail significant relationships between the each of the three factors, disability, intrusiveness, and depression, and a reduction in the disability - depression relationship after

intrusiveness is controlled.

In this study, despite significant zero-order relations as expected, the effect of disability on depression when intrusiveness was held constant, remained significant. Thus, in the strictest sense, the hypothesis that intrusiveness mediates the relationship between disability and depression was not supported. These results are not idiosyncratic though. In fact, in the study by Devins et al. (1992) the correlation of intrusiveness with depression was $r = .56$, $p < .001$, and of disability with intrusiveness was $r = .56$, $p < .001$, whereas the zero-order correlation of disability with depression was $r = .15$, $p > .05$. These results do not support the notion that disability exerts its influence on well-being via a mediator, intrusiveness, because there should be a significant relationship between the dependent and independent variable when the mediator is not included in the model. In the present study, there was nonetheless, a slight reduction is the absolute b value, which might suggest that a partial mediation model is more appropriate.

Admittedly, this model has been elaborated fairly recently (Devins & Seland, 1987; Devins et al., 1992). Much of the research examining this model has been based on evaluating the relationships between only 2 factors at a time: disability and intrusiveness, and intrusiveness and depression. Indeed, there has been substantial support for each of these relationships, in isolation, particularly the latter (Binik et al., 1990; Devins et al., 1984; Devins et al., 1986; Devins, Mandin et al., 1990; Devins, Mann et al., 1990). To this point, less research has focused on change in the disability - depression relationship after inclusion of a mediator.

To briefly summarize, this study did not support the age by intrusiveness interaction. Research in other illnesses has also failed to verify the existence of this

relationship (Devins et al., manuscript submitted). A significant relationship between disability and depression was found in this study that was not present in the study by Devins et al. (1992). Substantial research supports the present finding that such a relationship exists, which is required to demonstrate that the effect of disability on depression is via a mediator as is proposed in the model of the psychosocial impact of chronic illness presented by Devins et al. (1992). In fact, the results of the study by Devins et al. (1992) do not appear to support this model. Much other work, however, including the present study, supports the relationships between both disability and intrusiveness, and intrusiveness and depression. When the three variables are considered together, the results are less consistent. How then, can these seemingly contradictory results be reconciled?

A number of explanations have been proposed that may account for the differences in magnitude of the correlations between disability and depression found in various studies. Such explanations might also indirectly represent explanations for the occurrence of an age by intrusiveness interaction in one study and not another. There are three explanations offered here for the disparate results of this study and the Devins et al., (1992) study, which include methodological differences, differences in personal and contextual variables, and differing attitudes/perceptions of illness.

The first potential explanation might be methodological differences. Peck et al. (1989) suggest that the magnitude of the association between disability and depression is unclear partly because estimates of the size of the correlation often depend on methodological factors (i.e. which measurement scales are used). It is unlikely that methodological factors were the cause of the discrepant correlations in this case however, because the same

measurement instruments were used in both studies.

The second explanation is differences in contextual or person variables. Devins, Mandin et al., (1990) determined that well-being (eg. less depression) was found to be associated with fewer negative events, better social support, being employed, and being of higher SES. They note that these variables relate to well-being in normal healthy populations in the same way. Thus, the impact of RA also depends on these non-illness related variables. Differences between the RA sample used in this study and the one by Devins et al. (1992) on person and contextual variables such as these could also be an explanation for the inconsistency in results between the two studies. Both studies were, in fact, similar in the demographic variables measured, which therefore are unlikely to account for differences. However, there were variables such as social support that neither study measured that may have affected the results.

Lastly, Peck et al. (1989) provide further discussion of why the relation between these two variables (disability and depression) exists but is imperfect. They submit that such differences might be due to the presence of additional mediating variables [besides intrusiveness]. In particular, they consider such factors as helpless attitudes, interpretations of the disease, and degree of satisfaction with level of physical ability as three potential influences that could modify the relationship between disability and depression. They condense these hypotheses into a suggestion that the correlation between disability and depression might be larger among RA patients who are prone to maladaptive thoughts about their illness. Thus it may have been the case that patients in this study had more negative attitudes toward or perceptions of their illness than those in the study by Devins et al. (1992), although between-studies comparisons on this variable are not possible.

Perceptions of Severity as a Mediator

Nonetheless, data was available from the present study that could be used to test the hypothesis that perceptions of the illness affected the relationship between disability and depression. Perceived severity was used as a measure of illness perceptions, with greater perceived severity indicating a more negative outlook. The appropriateness of the use of severity as an indicator of perceptions about illness was substantiated by the fact that perceptions of severity were found to be a separate construct from disability (in partial correlation analyses).

Results indicated that in spite of a small reduction in the absolute value of the regression coefficient, the relationship between disability and depression remained significant even when perceptions of severity were held constant. Therefore the hypothesis that perceptions of severity would act as a mediator was not supported.

Perceptions of Severity as a Moderator

Even so, it may still be the case the perceptions of severity can function as a moderator. Neither the relationship between disability and depression, nor between intrusiveness and depression was moderated by perceptions of severity. There was however, support for the notion that perceptions of severity moderate the relationship between disability and intrusiveness (Fig. 2). Among those who perceived their illness to be severe, intrusiveness increased with increasing levels of disability. Conversely, intrusiveness actually decreased with increasing disability among those who perceived their illness to be less severe.

There are several possible ways to explain the finding that intrusiveness was lower at higher levels of disability among the patients who perceived their illness to be less severe. The first explanation is secondary gain. Perhaps if the illness is not believed to be severe, then increased

levels of disability may excuse the patient from some responsibilities, for example work, while at the same time increasing availability of more enjoyable leisure activities, attention from friends, family etc.
A second explanation might be that when illness is not perceived to be severe, people might explain their disability in other ways besides illness intrusiveness. In other words, they may attribute disability to something other than illness, eg. age, job. Third, it is possible that the lower level of intrusiveness when disability is higher is an indication of denial. Perhaps those who perceive their illness to be severe are different from those who do not in terms of their propensity towards denial. Even more generally, perhaps the difference in perceptions of severity reflects a difference in coping mechanism use. At low levels of disability, this difference might not be readily evident, whereas at higher levels, those who cope by information seeking for example (Felton & Revenson, 1984), may be more likely to perceive their illness as severe, whereas those who cope using denial might be more likely to perceive their illness as less severe, and even overcompensate with increasing disability. The feasibility of this proposal derives some support from the work of Felton, Revenson, and Hinrichsen (1984), which suggests that among the chronically ill, different coping strategies have specialized consequences.

This appears to be the first time that perceptions of illness have been investigated as either a mediating or moderating factor in the context of this model. Such perceptions could be a feasible explanation for the different results found in this study compared to that of Devins et al. (1992). Subjects in this study might have had more negative attitudes, or believed the illness to be different in terms of severity, although a comparisons between studies were not possible because attitudes were not

measured by Devins et al., (1992).

This explanation of differences between results within RA is strengthened by consideration of the fact that the age by intrusiveness interaction was not replicated among ESRD or MS patients (Devins et al., manuscript submitted). In their explanation of differences between conditions, Devins et al. (manuscript submitted) speculate that differences in the perceived severity across the three conditions may have accounted for the discrepant findings. They propose that high perceived severity might negate age-related expectations that would otherwise result in the age by intrusiveness interaction at low levels of severity. Unpublished field data supports inter-condition differences in perceived severity among RA, MS, and ESRD, $F(1,108) = 2389.28$, $p < .001$ (Saary, 1993). These findings are supported by earlier work by Wyler, Masuda, and Holmes (1968). This hypothesis was not extended to include intra-condition differences, however it is not unreasonable that even if a condition (eg. RA) is perceived as less severe than other conditions overall, there would still exist a range of perceived severities among patients within each condition, possibly making the interaction less likely among groups of patients who perceive a particular condition to be more severe.

Timing

The second goal of this study was to evaluate perceptions of the appropriate timing of rheumatoid arthritis in the lifespan, and to determine whether Neugarten's theory is useful in explaining the age by intrusiveness interaction. Unfortunately, this study did not replicate the interaction, however this does not immediately preclude an analysis of Neugarten's theory.

Despite the lack of support for the age by

intrusiveness interaction, the change in R^2 upon simultaneous addition of the two main effects (age and intrusiveness) in the regression analysis was significant, and therefore consistent with the results of Devins et al. (1992). Besides Devins et. al. (1992), others have acknowledged that Neugarten's proposal may account for observed age differences in responses to various life stressors, including chronic illness (Felton & Revenson, 1987; Mages & Mendelsohn, 1979; Lazarus & DeLongis, 1983). Overall however, in this study there were no relevant age effects per se, so Neugarten's theory cannot be applied directly in an explanatory sense.

Nonetheless, it was possible to do some preliminary empirical tests of the validity of the theory among RA patients. It was hypothesized that arthritis would be perceived across all age groups as a condition associated with old age. One reason for this assumption was that although RA actually occurs across the life span, it was hypothesized that perceptions might be overgeneralized from knowledge of osteoarthritis, which actually does occur only only among the aged. Its occurrence among various patients can be classified as off-time or on-time based on the degree of consistency between beliefs and the actual occurrence of the illness. Neugarten's theory would predict that people experiencing an off-time event, particularly an early event, would be more depressed.

Results suggested that among this sample of RA patients, arthritis was believed to be a condition that affects middle adults (age 35-64), not older adults as expected. Still, it was not surprising to find that younger people experienced more early off-time occurrence of RA than did the middle or older aged subjects. To evaluate whether depression scores were associated with timing, levels of depressive symptomatology for early, on-time and late

occurrences of RA were compared. At least among this sample of RA patients, Neugarten's hypothesis that off-time events are more traumatic was not substantiated; there was no difference in levels of depression as a function of the three timing groups (early, on-time, or late).

Nevertheless, trends in the data did occur in the predicted directions. Average depression scores for early, on-time and late occurrences were 17.7, 14.6, and 20.7 respectively for T1, and 16.9 and 14.8 for T2 (no late occurrences were reported for T2). This trend indicates that for both timing variables, depression was greater among people for whom the occurrence of RA was off-time (either early or late) as opposed to on-time. Curiously, those reporting a later than expected occurrence of RA were more depressed than those with either early or on-time occurrence.

Considering the trends are generally in the expected direction, sample size may be a limiting factor in this analysis. The sample size in this study was specifically selected to provide adequate power to replicate the interaction from the Devins et al. (1992) study, thus estimates of the population correlation coefficients for that analysis were available. For this particular analysis however, that sample size may have been inadequate, hence the non-significant effect of timing.

In summary, the results of this study have suggested that despite failing to replicate the age by intrusiveness interaction found by Devins et al. (1992), the relationship between disability and intrusiveness is indeed a valid one. This relationship appears to be moderated by perceptions of illness, specifically perceptions of the severity of the condition. A similar hypothesis was proposed by Devins et al. (manscript submitted) to explain inter-condition differences in the presence of the age by intrusiveness interactions. This study proposes that differences in the

perceptions of severity may be an equally viable explanation for discrepant results within the same condition (i.e. RA). Furthermore, although there were no significant differences in depressive symptomatology as a function of timing, trends in the data do indeed suggest that depressive reactions to RA may be greater when the occurrence of an illness is early rather than on-time. The trend that depression was greater among those with late illness timing than either those with early or on-time illness occurrence however, was unexpected.

Limitations

Several limitations of this study should be acknowledged. First, having adequate power to replicate the interaction of Devins et al. (1992) was the basis of determination of the sample size, thus with a larger sample, some of the non-significant timing effects may have been significant. In addition, although the sample size was calculated to ensure a power of .80, there obviously remains a 20% chance of Type II error. Furthermore, based on the response rate (43%) and the inclusion criteria discussed earlier, the sample obtained in this study might not be representative of all RA patients. Second, although trends in the data were discussed, they should be interpreted with caution, because the overall effects were not significant. Third, Hinkle et al. (1960) suggest that in the study of illness, the terms seriousness and severity, although roughly parallel, can have different meanings. Although the term seriousness was defined in the questionnaire (see Appendix), such a distinction was not explicitly made. Fourth, the correlational nature of this study precludes conclusions about causality. Fifth, this study was based on developing an understanding of the relationship between illness and depression, however the mean depression score for patients in this study was quite low (16.5), which could have affected the results. Finally, although the use of

regression rather than correlation coefficients in the mediational analyses reduces the influence of measurement error in the dependent variable, mediators are also measured with error. The result of measurement error in the mediator is that when all coefficients are positive, the effect of the mediator may be underestimated, whereas the effect if the iv on the dv could be overestimated (Baron & Kenny, 1986). This problem could be alleviated in future studies by gathering multiple measures of each variable, and using structural equation modelling (SEM) techniques for analysis.

Considerations for Future Research

There are also a number of other considerations for future research. First, greater attention should be paid to specific tests of mediation such as those performed in this study, rather than focusing primarily on individual correlations as support for hypothesized pathways. Second, although the Health Assessment Questionnaire has been used in conditions other than RA, (Daltroy et al., 1990; Goeppinger et al., 1988; Hochberg & Sutton, 1988; Lane et al., 1987; Rogers et al., 1989) most have been rheumatic conditions, and many studies modify the disability scale so it is more appropriate for that particular condition. Nonetheless, the HAQ disability scale is quite disease-specific and might not be appropriate for use in all other illnesses. However, caution should be exercised in comparing studies across conditions when different measures (of disability, for example) are used in each condition.

Bearing in mind the above considerations, future research might attempt to observe whether changes in the association between disability, intrusiveness, and depression occur as a result of changes in perceptions about the severity and appropriateness of timing of the illness. Other perceptions (cf. Lau et al., 1989; Leventhal, 1984) about illness and their relation to disability and

depression among chronically ill patients would also be worthy of further study. It might also be interesting to use discriminant function analysis to attempt to predict whether patients would fall into a high or low intrusiveness group (at a fixed level of disability) on the basis of perceptions of severity, depression scores, and perhaps coping style as well.

Many have acknowledged a link between appraisals of control and both pain (Jensen & Karoly, 1991) and adaptation to rheumatoid arthritis (Affleck et al., 1987; Felton & Revenson, 1984; Nicassio et al., 1985; Tennen et al., 1992). However, these relationships appear to be confounded by illness severity (Christensen et al., 1991; Jensen & Karoly, 1991; Tennen et al., 1992). Considering that perceptions of severity moderated the disability-intrusiveness relationship in this study, and that severity has also been shown to affect the control-adaptation relationship, future research should focus on understanding the relationships among all of these variables by continuing to develop more integrated models to explain the psychosocial impact of chronic illness.

In fact, Devins et al. (1993) have expanded the Devins et al. (1987, 1992) model to include control as a partial mediator of the intrusiveness-depression relationship in multiple sclerosis. Interestingly, Felton and Revenson (1987) found that the dimensions of control and severity were not independent of each other. So, in light of the facts that: 1) control and severity may not be completely separate constructs, and 2) that in this study perceptions of severity moderated the disability-intrusiveness relationship in RA, whereas control was proposed to mediate the intrusiveness-depression relationship in multiple sclerosis, there appears to be a need to assess the generalizability of models of the psychosocial impact of chronic illness from one illness to another.

Implications

There are several important implications of this research, both for RA patients, and for practitioners and other professionals working with these patients. This study has shown that illness appears to impact on a patient differently as a function of his or her perceptions of severity, and that, albeit non-significant, trends suggest that depressive reactions to RA may be greater when the occurrence of an illness is off-time rather than on-time. Taken together, it seems that perceptions about illness play an important role in the psychosocial impact of illness. This finding is consistent with a large body of literature affirming the importance of cognitive factors in the development of depression (Beck, 1963, 1964). Considering that perceptions cannot be thought of as equivalent to objective measures of a construct, it would be relevant to assess patients' perceptions of their illness apart from more objective measures of a similar construct. This may facilitate the identification of those at greater risk for depression due to negative perceptions. It may be the case that these beliefs about illness are more easily changed than the physical status of the condition itself. If this is so, then the effectiveness of interventions to prevent depression may be enhanced if perceptions are the point of initiation. Considering that utilization of health care services often increases when psychological distress occurs in conjunction with physical illness, such preventive efforts may enhance the cost-effectiveness of health care delivery. Clearly then, if the best treatment of disease includes consideration of non-physical components of health such as psychosocial well-being, it is a worthy endeavour to develop a more holistic understanding of the consequences of illness. Overall, it would be beneficial to add such perceptions into a model of the psychosocial impact of chronic illness.

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APPENDIX

Questionnaires and Consent Form

CONSENT FORM FOR PARTICIPANTS IN THE ARTHRITIS PSYCHOSOCIAL IMPACT STUDY

Research Project: Age Differences in the Psychosocial Impact of Chronic Disabling Conditions

Investigators: Dr. S.M. Edworthy, Ms. M.J. Saary, Dr. C. Konnert

Funding Agency: The University of Calgary

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The purpose of this research is to investigate the effect of chronic illness on mood, and to examine whether the effect differ with age. Previous research has shown that some people with chronic illnesses experience changes in their mood and that people of various ages respond differently to having a chronic condition such as arthritis. Results will increase our understanding of why these age differences occur.

Your decision to participate in this research in no way interferes with your regular medical care and if you wish, you will be informed about the results at the end of the study. There are no risks associated with participation in this project; however, should it become apparent that you are in need of additional treatment, an appropriate referral will be made on your behalf.

Participation in the study will mean the completion of a questionnaire which will take approximately 20-30 minutes, and release of arthritis-related clinical findings from your medical chart. All information gathered will be kept strictly confidential; data will be kept in locked file and results will be reported only in an anonymous averaged format. You will be assigned an ID number so that your identity will not be known to anyone other than the investigators listed above.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Joan Saary, Graduate Student, 220-5518 or
Dr. C. Konnert, Assistant Professor, 220-4976 or
Dr. S. Edworthy, Principal Investigator, 220-7740

If you have any questions concerning your rights as a possible participant in this research, please contact the office of Medical Bioethics, Faculty of Medicine, The University of Calgary at 220-7990.

_____

Name

_____

Signature of Subject, or Responsible Proxy if applicable

_____

Name of Witness

_____

Signature of Witness

_____

Date (day/month/year)

A copy of this consent form will be given to you. Please keep it for your records and future reference.

Background Information

Please indicate your gender: Male Female Age: _____ years

What is your marital status? (please circle the number of your answer)

1 Single
2 Married
3 Separated
4 Divorced
5 Widowed
6 Other (specify) _____

How may children do you have? (include stepchildren) _____

How many children are still living at home full time? (include stepchildren) _____

What are the ages of the children living at home? _____

How many years of education do you have? (please circle the number of years)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26+

What is the highest degree, certificate, or diploma you have earned?

1 no certificate, degree, or diploma
2 secondary school graduation certificate
3 trace school and other non-university certificate or diploma
4 university certificate, diploma, or degree
5 other (specify) _____

What is your employment status?

1 Working (full time)
2 Working (part time)
3 Unemployed
4 Retired
5 Homemaker
6 Student
7 Other (specify) _____

What is your occupation? _____

What is your total family income before taxes?

1 Under $15,000
2 $15,000 - $29,999
3 $30,000 - $44,999
4 $45,000 - $59,999
5 Over $60,000

1) **In general, how much does this condition affect or interfere with lifestyles, activities and interests?** (ie. How intrusive is this condition?)

1 = condition does NOT affect lifestyles, activities, and interests very much (condition is not very intrusive)

7 = condition affects lifestyles, activities, and interests very much (condition is very intrusive)

Condition	1 not very much	2	3	4	5	6	7 very much	Don't Know
Arthritis								
Asthma								
Diabetes								
Epilepsy								
Multiple Sclerosis								

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2) **The SERIOUSNESS of an illness can be thought of in a number of ways, such as:**

disabling - not disabling
incurable - curable
life threatening - not life threatening
long term - short term

Considering all these aspects and others like them, how SERIOUS is this condition?

1 = condition is NOT very serious
7 = condition is very serious

Condition	1 not very much	2	3	4	5	6	7 very much	Don't Know
Arthritis								
Asthma								
Diabetes								
Epilepsy								
Multiple Sclerosis								

3) **Illness conditions are often associated with a certain life stage. For example, some illnesses are said to be "childrens' illnesses," and others are said to be "diseases of old age."**

Please indicate which age group(s) you believe to be MOST associated with each of the following conditions. (i.e. which group of people are most likely to have the condition?)

*if you believe more than one group is affected, please put a 1 in the box of the MOST affected, a 2 in the box of the next most affected, and so on.

Condition	Children & Adolescents 0-17	Younger Adults 18-34	Middle Adults 35-64	Older Adults 65+	Don't Know
Arthritis					
Asthma					
Diabetes					
Epilepsy					
Multiple Sclerosis					

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **PAST WEEK** by checking the appropriate space.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with the help from my family				
4. I felt that I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people disliked me.				
20. I could not get "going".				

In this section we are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments on the back of this page.

Please check the one response which best describes your usual abilities OVER THE PAST WEEK:

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	Unable To Do
Dressing & Grooming				
Are you able to: -Dress yourself, including tying shoelaces and doing buttons?	_____	_____	_____	_____
-Shampoo your hair?	_____	_____	_____	_____
Arising				
Are you able to: -Stand up from an armless straight chair?	_____	_____	_____	_____
-Get in and out of bed?	_____	_____	_____	_____
Eating				
Are you able to: -Cut your meat?	_____	_____	_____	_____
-Lift a full cup or glass to your mouth?	_____	_____	_____	_____
-Open a new milk carton?	_____	_____	_____	_____
Walking				
Are you able to: -Walk outdoors on flat ground?	_____	_____	_____	_____
-Climb up five steps?	_____	_____	_____	_____

* Please check any **AIDS OR DEVICES** that you usually use for any of these activities:

_____ Cane

_____ Walker

_____ Crutches

_____ Wheelchair

_____ Devices Used for Dressing (button hook, zipper pull, long-handled shoe horn, etc.)

_____ Built Up or Special Utensils

_____ Special or Built Up Chair

_____ Other (Specify:_____)

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

_____ Dressing and Grooming _____ Eating _____ Arising _____Walking

*Please check the one response which best describes your usual abilities **OVER THE PAST WEEK:**

	Without **ANY** Difficulty	With **SOME** Difficulty	With **MUCH** Difficulty	**Unable** To Do
HYGIENE				
Are you able to: -Wash and dry your entire body?	____	____	____	____
-Take a tub bath?	____	____	____	____
-Get on and off the toilet?	____	____	____	____
REACH				
Are you able to: -Reach and get down a 5 pound object (such as a bag of sugar) from just above your head?	____	____	____	____
-Bend down to pick up clothing from the floor?	____	____	____	____
GRIP				
Are you able to: -Open car doors?	____	____	____	____
-Open jars which have been previously opened?	____	____	____	____
-Turn faucets on and off?	____	____	____	____
ACTIVITIES				
Are you able to: -Run errands and shop?	____	____	____	____
-Get in and out of a car?	____	____	____	____
-Do chores such as vacuuming or yardwork?	____	____	____	____

* Please check any **AIDS OR DEVICES** that you usually use for any of these activities

____ Raised Toilet Seat

____ Bathtub Seat

____ Jar Opener (for jars previously opened)

____ Bathtub Bar

____ Long-Handled Appliance for Reach

____ Long-Handled Appliance in Bathroom

____ Other (Specify _____)

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

____ Hygiene

____ Reach

____ Gripping and Opening Things

____ Errands and Chores

We are also interested in learning whether or not you are affected by pain because of your illness.

* How much pain have you had because of your illness IN THE PAST WEEK?

PLACE A MARK ON THE LINE TO INDICATE THE SEVERITY OF THE PAIN

NO PAIN — VERY SEVERE PAIN

0 |——————————————————————————————| 100

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION. If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave an items unanswered. Thank you.

1. How much does your illness and/or its treatment interfere with your HEALTH (i.e., how well you feel physically)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

2. How much does your illness and/or its treatment interfere with your DIET (i.e., the things you eat and drink)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

3. How much does your illness and/or its treatment interfere with your WORK?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

4. How much does your illness and/or its treatment interfere with your ACTIVE RECREATION (e.g., sports)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

5. How much does your illness and/or its treatment interfere with your PASSIVE RECREATION (e.g., reading, listening to music)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

6. How much does your illness and/or its treatment interfere with your FINANCIAL SITUATION?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

7. How much does your illness and/or its treatment interfere with your RELATIONSHIP WITH YOUR SPOUSE (or with your girlfriend or boyfriend, if you are not married)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

8. How much does your illness and/or its treatment interfere with your SEX LIFE?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

9. How much does your illness and/or its treatment interfere with your FAMILY RELATIONS?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH

10. How much does your illness and/or its treatment interfere with your OTHER SOCIAL RELATIONS?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH

11. How much does your illness and/or its treatment interfere with your SELF-EXPRESSION/SELF-IMPROVEMENT?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH

12. How much does your illness and/or its treatment interfere with your RELIGIOUS EXPRESSION?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH

13. How much does your illness and/or its treatment interfere with your COMMUNITY AND CIVIC INVOLVEMENT?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH

14. Overall, how free or restricted do you feel in doing what you might want to do?

I STILL DO EVERYTHING I WANT TO DO	1	2	3	4	5	6	7	I CAN NO LONGER DO ANY OF THE THINGS I WANT TO DO

15. How much does this bother you?

NOT VERY MUCH	1	2	3	4	5	6	7	VERY MUCH