

Management of Rheumatoid Arthritis:
An Exploration of Individual's Perceptions of Efficacy and
Use of Alternate Treatment Modalities and Conventionally
Prescribed Treatments

by

Diana Pallen

A thesis
presented to the University of Manitoba
in partial fulfillment of the
requirements for the degree of
Master Of Nursing

Winnipeg, Manitoba

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the University of Manitoba in partial fulfillment of the requirements
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ABSTRACT

A chronic condition such as Rheumatoid Arthritis (R.A.) often has a varied impact. As a result, the affected individual may turn to treatments other than those prescribed in an effort to manage the condition. The purpose of this exploratory study was to determine the perceptions of knowledge, efficacy and use of conventionally prescribed (CTM) and alternate treatment modalities (ATM) in the management of R.A.

A sample of seventeen (n=17) adults with R.A. was interviewed using 23 open-ended questions to determine perceptions. Findings suggest that perceived benefit/risk and belief/faith were important factors. All subjects reported using CTM's consistently. All expressed knowledge of ATM's, but with a conservative, sporadic use reported. Knowledge, it's source, disease condition, support, resources, cost and remission were other relevant factors which emerged in modality consideration and use.

The management of arthritis entailed a variety of self reliant and other reliant coping strategies.

Limitations of the study are identified. Implications for nursing practice and education are discussed. Recommendations for future research are offered.

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To my family - my parents, Laura and Tony,
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those coping with Rheumatoid Arthritis.

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Chapter I

STATEMENT OF THE PROBLEM

The Prevalence of various chronic illnesses has increased markedly over the past few decades (Anderson & Bauwens, 1981). Such highly visible diseases as cancer, cardiovascular conditions, diabetes, pulmonary diseases and rheumatic diseases are but a few examples of the shift from infections to unresolved chronicity in disease (Wiener, Fagerhaugh, Strauss & Suczek, 1982).

Collectively, these diseases have an impact on both the effected individual and society. For the individual, the symptoms produced by the disease interfere with normal daily activities. Often, the medical regimen as prescribed is limited in its effect and treatment, and while intended to ease the suffering, may actually contribute more to the disruptions of daily life. It is particularly costly to the individual in terms of the suffering as well as the loss of social relationships and productivity in economic terms. Devereaux (1986) noted that in Canada in 1978 an average of 11.1 work days were lost annually due to arthritis in its various forms.

Cost is also associated with the development of technologies which have been created, in part, to deal with the affects of chronic diseases. It must be stressed that for the most part these diseases cannot be cured, but can only be managed (Anderson & Bauwens, 1981). Costly technologies,

which ameliorate incapacitating effects of disease but do not cure, have been coined as being "halfway technologies" by Thomas (1974). With an endless round of visits to the physician's office, admissions to hospitals and subsequent discharge to manage the illness at home, it is not surprising that those suffering with a chronic disease might turn to non-prescribed alternate treatment modalities or remedies because no cure or even effective treatment is in sight. Cost may also be a factor, for as Strauss, Corbin, Fagerhaugh, Glaser, Mainen, Suczek and Wiener (1984) note, the composition of chronic illness necessitates a management of their daily existence under specific social and financial conditions. If great or even unmanageable expense is involved with the prescribed treatment regimen, self-medication or alteration in the prescribed regimen is likely.

Regimen modifications may also occur through others dissuading them with accounts of personal experiences or hearsay pointing to "better ways". Cultural and ethnic affiliations, may combine with a perception of the inadequacies of technology to manage or cure the condition (Strauss et al, 1984) to contribute to a trying out of other modalities. Thus a multiplicity of reasons may exist for turning to other ways of managing the condition.

The impact of chronicity with its resulting tendency to search for other methods of treatment or care, is reflected in the disease entity known as arthritis. Arthritis is one of

115 known types of inflammatory conditions which affect the joints or related systems and are listed under the general classification of Rheumatic Diseases (Rodnan & Schumacher, 1983). Evidence, cited by Devereaux (1986), shows that 16% of Canadians suffer from some form of arthritis. Being female and aging increases the likelihood of developing some form of arthritis (Rodnan & Schumacher, 1983; Devereaux, 1986). It is reported that 1.3% of the population develops some form of arthritis before the age of 15 years (Devereaux, 1986).

Rheumatoid Arthritis, as a specific rheumatic disease, is characterized by progressive destruction of the involved joints as well as by unpredictable remissions and exacerbations in the disease. No specific cause or cure has been identified by scientific research as yet (Rodnan & Schumacher, 1983).

Conventional treatment prescribed includes a combination of medication, rest and exercise as well as education about the disease and its management. The aim of the prescribed, conventional regimen is to relieve pain, reduce inflammation, minimize the effects of the disease and maintain as much joint function as possible (Rodnan & Schumacher, 1983; Luckmann & Sorensen, 1980).

Despite the use of more effective and safer drugs as well as the individualized planning of the arthritic person's activity and rest regimen, the aims of relieving pain and minimizing the effects of the disease are not always achieved.

Chronic pain, frustration and hopelessness often result (Miller, 1983). Thus, individuals affected with Rheumatoid Arthritis (hereafter referred to as R.A.) tend to drift from the physician's supervision and also the prescribed medication. In citing the Canada Health Survey, Devereaux (1986) noted that:

"only about 16% of people reporting arthritis were taking medications, which means that, by far, the majority lapse from regular drug therapy and suffer the consequences" (p.3).

The same study noted that more than half (62%) had seen a physician about their condition, but approximately a third were also seeing a chiropractor. Other alternate treatment modalities employed by those with R.A. have included such diverse practices as use of diet therapy, topical lotions, vitamins, jewellery made of specific metals and trips to different climates (Kronenfeld & Wasner, 1982).

It would appear that the use of alternate modalities or remedies in the treatment of R.A. by the individual is not uncommon (Devereaux, 1986; Kronenfeld & Wasner, 1982). There has been an identified dearth of systematic studies in this area. Kronenfeld and Wasner (1982) concluded that further study was warranted particularly from the perspective of the lay culture which they noted tended to use medical and folk models concurrently. They further recommended that variables related to the diseases, the client and the alternate remedies needed to be explored.

Purpose of the Study

As such, the general purpose of this study was to explore the adult arthritic individual's perceptions: 1. in relation to conventional, prescribed treatment and adherence to that regimen; and 2. in relation to alternate treatment modalities, their efficacy and use in the self care and management of the arthritic condition.

The specific purposes of this study were to explore:

1. The perceptions of arthritic individuals regarding the prescribed conventional treatment regimen (ie: in terms of their general knowledge of the disease and the treatment).
2. The perceptions of arthritic individuals regarding the efficacy of conventional, prescribed treatment.
3. The perceptions that arthritic individuals have regarding the use of, or adherence to, conventional prescribed treatment.
4. The perceptions that arthritic individuals have regarding alternate treatment modalities (ie: general knowledge or awareness of).
5. The perceptions that arthritic individuals have of the efficacy of alternate treatment modalities.
6. The perceptions of arthritic individuals in relation to individual experience or personal practices with alternate treatment modalities.

7. The perceptions of arthritic individuals of the value of combining conventional and alternate treatment modalities.

In order to facilitate data gathering, a variety of pertinent questions was used (See Appendix A).

Several rationale may be noted for pursuing this study. It is noted by Rodnan and Schumacher (1983), that "...physicians and allied health professionals are responsible as soon as the diagnosis has been confirmed for educating the patients and family and providing hope and motivation for their participation in the management of the disease" (p.46). Review of the literature and personal, clinical experience indicate that individuals who are experiencing a chronic disease tend to manage their own disease using an alternate modality of some form which has not been specifically prescribed by the physician. Data from personal experience had not been systematically gathered. Discussion of alternate treatment modalities has been seen increasingly in the popular press and other media forms, but little systematic exploration has been documented in the professional literature.

As health care professionals, nurses accept their responsibilities for educating the client in order to be able to foster responsible self-care. It is important that the nurse know whether "patient teaching" is actually educating the individual toward effective self-care.

There has been a growth of self-care and self-help movements in society over the past few decades. Individuals play a more active part in the decision making process, particularly as it contributes to self care. Combined with this is a greater awareness of and a shift to holism and to a healthier, more natural lifestyle. Nursing must be aware of both and be prepared to meet patient needs accordingly.

Through the use of collected, pertinent data, an exploration of the individual's perceptions and practices should provide further insight in the chosen problem area. This will in turn form a basis for educating nurses for dealing with clients' Rheumatoid Arthritis.

Chapter II

CONCEPTUAL FRAMEWORK

The conceptual framework chosen to guide this research is derived from the model of self-care developed by Orem (1985). While it is based primarily on some of the concepts offered by Orem (1985), concepts basic to human interaction within a health care provider and care receiver relationship have also been incorporated. Communication is an integral component of interactions and is important in those which offer support and education for the purpose of facilitating self care. Furthermore, it is assumed that self care may take the form of using the conventional treatment system or using alternatives as an adjunct or substitute to conventionally prescribed treatments.

Orem's (1985) was selected as the main contributing model because of its holistic focus. It includes the individual's interaction with the overall environment and how that may in turn affect health and well-being. Chang (1980) notes that there is a variety of roles in selfcare which includes "health maintenance, disease prevention, self-diagnosis, self-medication, self-treatment, and patient participation in use of professional services" (p.43). The conceptual framework employed considers the individual in relation to his/her disease, health, environment (both physical and social) and health care providers.

Basic Underlying Concepts:

The principal concepts underlying self care are used in this study's framework and include Person, Environment, Health and Health Care provider. Following is a brief delineation of each. Person is viewed as the individual who is a holistic, functional unit in society and who has individual needs, beliefs, values and attitudes. As well, the person has different experiences, perceptions and expectations which are reflected in decisions and judgements about self care.

The Environment consists, in part, of society, which plays a part in helping to form an individual's perception about health and illness. It is seen as influencing expectations for a person's behaviour (Fitzpatrick & Whall, 1983). Person and Environment are seen as parts of an integrated system in which each interacts with the other. This interaction may be physical, social or psychological. The environment, as greater society, provides a developmental milieu which ideally helps the person achieve normal maturation.

Health is viewed as reflecting the wholeness or integrity of the person in physical (biological), psychological, emotional and social terms. It is reflective of the individual's capacity to live as a human being in a holistic context and achieve some measure of potential. Health is dynamic, rather than static.

An individual's perception of health and illness may

fluctuate. This is true also in the midst of a disease such as R.A. which has an identified pathological process. Illness may be considered a perception of being unwell, of being unable to fulfill one's roles (Baranowski, 1981). Health is not conceived of as a mere absence of illness or disease, but is rather one's state of wellness and illness. This view is not supported entirely by Orem (1985) who suggests that any deviation from normal structure or function is "properly referred to as an absence of health in the sense of wholeness or integrity" (p.174). While there is validity in this approach, it nevertheless does not focus sufficiently on the health or healthy behaviours, of the individual. Payne (1985) has expressed the definite need to address and describe healthy behaviour from the person's viewpoint, while recognizing that health is inherent in all areas of life. Finally, health is experienced in a social or environmental as well as individual context. As Baranowski (1981) has suggested, if one considers health and wellness as something beyond that which can only be defined biologically, then social values, norms and functioning also need to be considered.

Health care providers who seek to promote the health of individuals are considered to be those with advanced knowledge and preparation in a given area, which may or may not be scientifically based, and who share the expertise (in whatever form or level) with the individual person by physically

assisting or by providing information or support. This care provider may be prepared by and for society by conventional, recognized means reflective of the scientific method and the biomedical model (e.g. schools of medicine, nursing, pharmacy ...). For the purpose of this framework, these individuals are referred to as conventional health professionals or conventional health care providers. Those who are prepared by methods not readily recognized by greater society and its dominant educational institutions are referred to as alternate health care providers (e.g. chiropractors, herbalists, acupuncturists, therapeutic touch healers).

Self-Care

As Orem (1985) notes, all individuals have self care needs due to normal growth and development within the life cycle. She has defined self care as the "production of actions directed to the self or to the environment in order to regulate one's functioning in the interest of one's life, integrated functioning and well being" p.31. It involves voluntary action which is learned and has purpose. When it is effectively performed it maintains not only life, but a quality of life inherent in health and wellbeing. As adjuncts to the above are the presuppositions that self-care requires self management and that self care is a form of self regulation and is necessary for health and development. It also assumes that individuals have not only responsibility for self care, but also a right to make decisions and take actions

which will promote effective functioning in developing their potential for health. Self care is not static. The ability to care for oneself may vary not only amongst individuals, but also within any given individual. This ability is reflected in the capacity for self-care agency. In addition, an individual's abilities to engage in self-care are affected by age, developmental state, life experience, sociocultural orientations and conditions as well as resources and health (Orem, 1985).

Self Care Needs

A deviation in health, reflecting a deviation from normal structures or function occurs with the imposition of a chronic disease, such as Rheumatoid Arthritis. Due to varying effects of the disease, health related limitations are produced which in turn alter self care needs. These altered needs or requisites produced by a change in structural or functional health state may occur in addition to universal and developmental selfcare needs which are common to all humans.

Universal self-care needs consist of such requisites as the maintenance of air, water, food and elimination as well as a maintenance of balance between activity and rest and solitude and social interaction. Others needs are the promotion of human functioning and development within social groups "in accordance with human potential, known human limitations, and the human desire to be normal" (Orem, 1985, p.91). The developmental self-care needs which "support life

processes and promote the process of development" as outlined by Orem (1985), articulate with the universal needs (p.96). Attention to these needs requires, in part, a provision of care which either prevents or overcomes the effect of conditions such as those associated with R.A. These conditions might include special needs reflected in problems of social adaptations, loss of friends, relatives or occupational security or those needs related to poor health or disability.

Self care needs exist for all individuals who have an injury, illness or pathology of some kind. Rheumatoid arthritis, partly because of its remissions and exacerbations, produces not only a definite, but also a varying effect. Developmental needs for a restoration to normalcy demands that action be taken. "In modern [Western] society this would be expressed as a demand for medical diagnosis and treatment. Seeking and participating in medical care for health deviations are self-care actions" (Orem, 1985, p.98). These actions are responses to effects of the condition and reflect a self care demand for healing or restoration.

These demands may result in seeking treatment which takes the form of obtaining medical assistance and information about the disease and its specific treatment. It also entails being able to accept oneself and learn to live with the condition.

Self Care Deficit

If the demand for care is greater than the person's

agency (capacity to act) to meet it, then a deficit would exist. It is important to note, that ultimately it is the individual who will determine his/her own deficit, based on individual perceived need and capacity to meet need.

Generally, when a perceived deficit exists the individual turns to others who may take the form of members of social networks (family, peers, or friends). Conventional health care systems or alternate systems may be sought out (Norris, 1979). Alternate systems are often considered marginal by the conventional medical establishment (Kronenfeld & Wasner, 1982). When self agency, is perceived to be insufficient the agency of others is used in order to provide effective, therapeutic care which in its healing capacity is supportive or remedial.

Role of Health Care Providers

Regardless of whether the conventional or alternate health care system is chosen it is assumed that the practitioner offering the care would have restoration, maintenance, promotion of structural or functional integrity and prevention of future impairments as goals of care. The goal is to achieve a greater degree or quality of health.

The nursing agency (ability to act on behalf of others) may be enacted through any one of three "nursing systems: wholly compensatory, partly compensatory or supportive educative" (Orem, 1985, p.152). The final system, the supportive educative involves situations "where the patient is

able to perform or can and should learn to perform required measures ... of therapeutic self-care but cannot do so without assistance" (Orem, 1985, p.156). Assistance in these situations could include guidance, support, teaching and provisions of a developmental environment. Thus, the acquisition of knowledge and skills and making decisions are important components. Because most individuals with R.A. function with varying degrees of independence in society, the supportive educative system has been chosen for this research.

Provider-Client Interaction

Regardless of which provider group is approached and utilized, an interrelationship is established. The interrelationship requires interaction and thus presupposes communication. Effective communication is the "lifeblood of the helping relationship" (Spradley, 1985). As well as information and ideas, attitudes and values are also conveyed. (Spradley; Gerrard, Boniface & Love, 1990).

In order for effective self care to take place, it requires that the individual become an active participant in the care and its planning, and that there be appropriate identification of goals based on the individual's needs, experiences, expectations, values and beliefs. Finally, communication and therefore effective interaction may be hindered if there is a discrepancy between the values of the individual and the health care provider.

In summary, any individual is not only capable of

self care, but actually engages in self care activities on a day to day basis in order to maintain integrity in different areas. When an illness such as R.A. strikes, the ability to care for oneself is challenged. Health and any deviation from it, is perceived and valued differently by individuals. Individuals may turn to a variety of resources. Actions to facilitate self care in the midst of a disease condition may include turning to either conventional health care providers or alternate health care providers or both, with the one complementing the other. Whichever choice for self care is made, communication remains a key component in any interaction and interrelationship.

Chapter III

LITERATURE REVIEW

Introduction

The following selected review of the literature addresses the etiology of R.A., and the nature of its impact on the physical and psychosocial health of the individual. The roles of self care, society and self help groups in the management of the disease are also considered. In addition, the literature review addresses the nurse's role in promoting self care and the importance of interpersonal communication and decision making as they relate to self care practices. Some conventionally prescribed treatments and alternate modalities which are available to assist individuals with arthritis to manage their disease are also briefly considered.

Etiologic Considerations

Management of R.A. and reduction in health deviation are partly confounded by the nature of R.A. While no known cause or cure has been found for R.A. (Rodnan & Schumacher, 1983; Porter, 1984), research has been vigorous and promising in the area of its etiology. While it appears that the arthritic diseases have affected humans for several thousand years, paleopathologic findings appear to suggest that R.A. is a relatively recent disease (Klepinger, 1979; Kean & Buchanan, 1983). In fact, in its modern form, evidence of R.A. was first documented in the early 19th century (Kean & Buchanan, 1983).

More recent research studies have focused on specific causative factors. R.A.'s relationship to the immune system has been documented increasingly. Cellular immunology has been found to be abnormal in individuals with R.A. (Kean & Buchanan, 1983; Stuart & Kang 1986).

Research has also studied the relationship between sex steroids and autoimmunity. A study of animals by Schuurs (1985) found that sex steroids have a negative affect on autoimmunity particularly in females, who exhibit a higher incidence of R.A. Gestation appeared to affect symptoms adversely as did the use of oral contraceptives. Schuurs (1985) concluded that further research needed to be done in the area.

Genetics have also been studied by researchers as a factor in R.A. Certain cell elements have been demonstrated in increased amounts in subjects with R.A. and in healthy subjects with strong family histories of R.A. (Kean & Buchanan, 1983; Zoschke & Segall, 1986).

Research has also considered the role that exogenous, environmental agents may play in causing R.A. A study by Kahan, Kahan, Amor and Menkes (1985) considered the relationship between the Epstein-Barr virus (EBV), the immune system and R.A.

Valtonen, Leirisalo, Pentikainen, Rasanen, Seppala, Larinkari et al (1985) studied infectious agents that possibly triggered reactive arthritis. They concluded that the

identity of the agent had little effect on the clinical manifestation of the reactive arthritis. Other researchers who have focused on reactive arthritis have concluded that synovial lymphocytes need to be examined in reactive arthritis particularly when results of peripheral lymphocytes are inconclusive (Ford, da Roza & Schulzer, 1984; Mims, Stokes & Grahame, 1985).

While the etiology of R.A. has not as yet been specifically identified, research continues in the area and studies conducted suggest areas for further exploration. While findings of studies provide hope, uncertainty remains for those affected because of a lack of definitive causative factor.

The Impact of R.A.

Unknown etiology is one facet of the uncertainty associated with R.A. for the individual. Uncertainty may also be the result of not being able to predict with any certitude the disease course and degree of involvement for any given affected individual (Rodnan & Schumacher, 1983).

While etiology may not be known, the impact of the disease on the physical and psychosocial status of individuals has been studied and is well documented.

Overall Physical Effect

Cosh (1984), when addressing survival and death rates in relation to R.A., noted that "on the whole R.A. does shorten life, although there is no unanimity on how or how much it

does so" (p.117). Cosh (1984) also suggested that age of onset, the effect of drugs, the severity of the disease as well as other factors have all been considered in mortality related to R.A. He concluded that more data need to be collected on the relationship between these factors and mortality.

The presence of any one or more of the above factors may complicate the course of the R.A. which Rodnan and Schumacher (1983) have noted may be highly inconsistent, and manifest itself as an illness of brief duration with an extended remission period, or as a "relentlessly, progressive destructive polyarthrititis ..." (p.40). This further compounds the sense of uncertainty.

While characteristically a joint disease, a number of other tissues may be involved in R.A. (Rodnan & Schumacher, 1983; Panush & Yonker, 1984; Cosh, 1985). Skin involvement in the form of nodules, occurs in 20-25% of patients. Cardiac involvement is fairly common with coronary arteritis being reported in 20% of patients with R.A. (Panush & Yonker, 1984). Pulmonary manifestations are more common with one half of those with R.A. found to have pleural disease on autopsy (Panush & Yonker, 1984). Anemias are relatively common in individuals with R.A. and may reflect many contributing factors (Panush & Yonker, 1984). On the whole, as Rodnan and Schumacher (1983) note "extra articular manifestations probably occur frequently but are usually occult and of

limited physical significance" (p.42). Nevertheless, for those affected by any one or more of the above, there are implications for overall health status, general well being and ability to perform activities of daily living.

Health Status Effect

While the disease may not manifest beyond the joints, the impact of the disease in its usual form may be significant. In a study of health status in six different chronic diseases, Mason, Weener, Gertman and Meenan (1983) concluded that individual with R.A. and pulmonary diseases produced a poorer health status than those with diabetes, cardiac disease, cancer or hypertension. Items considered physical, psychological and social health status. Participants (N=322) were comparable in terms of demographics (ie gender, race, employment, education, marital status, income). Measures of health status included such items as mobility, dexterity, physical activity, social activity, anxiety, depression, pain and general health perceptions. Analysis of variance was used to explore the relationships of different chronic diseases on the health status measures. Differences among the chronic diseases were notable for physical activity, dexterity and pain. Only pulmonary patients fared worse than those with R.A. on mobility. They concluded that health status scores for the chronic disease studied were significantly different, except along the psychological dimension. Those with R.A. ranked the lowest in physical activity, dexterity, household

activities, social activity and pain. They concluded that while R.A. is not a fatal disease, "chronic R.A. is most certainly a very morbid condition for a vast majority of patients" (p.765).

Pain Affect

Pain has been closely associated with R.A. Pain is a subjective experience with individuals displaying a large variation in the response to pain (Kazis, Meenan & Anderson, 1983; Meinhart & McCaffery, 1983). This may reflect "the patient's history with the illness, the duration of the disease, the type of pain experiences and the psychosocial and cultural make-up of the individual" (Kazis, Meenan & Anderson, 1983, p.1017). In a letter published in the Annals of the Rheumatic Diseases, (1985) McKenna and Wright indicated that rheumatologists may underestimate their patient's desire for pain relief. They noted, of a random sample of patients with R.A., 47% ranked pain relief as the "most desirable objective." Those who ranked disability above pain in importance were patients with end stage disease who had deformities without active joint involvement. McKenna and Wright (1985) concluded that success of treatment may be assessed by the individual's relief of pain. Pain in the health status and health behaviour of patients with R.A. was also evaluated by Kazis, Meenan and Anderson (1983). Physicians' assessment and patient assessment of pain were compared. In physician assessment of an individual's

functional status, pain provided a substantially less explanatory power than physical status. In patient assessment, pain was the most important contribution for explaining patient assessment of general health and overall arthritis status. Kazis et al (1983) concluded that pain, psychological factors and physical disability needed to be considered in the management of R.A.

Impact on Universal and Development Needs

The impact of R.A. on the individual's ability to meet universal and developmental requisites must also be considered. Orem (1985) suggests that individuals strive for normality, attainment of realistic and positive self concept and esteem and of a balance between rest and activity and solitude and socialization. Poor health, deprivation in education, problems with social adaptation, loss of friends and loss of occupational status are associated with the effect of R.A. and could block the meeting of life goals.

This blocking or hindering of the meeting of need may be viewed as a disruption. The impact of R.A. as a disruptive event has been well documented. In an English study of 30 patients with R.A., Bury (1982) noted that as a chronic illness, R.A. produces disruptive events. Individuals experience these events uniquely, and describe them differently as disruption. Bury's (1982) study explored the recognition and changes in life situations and relationships experienced by each of the 30 subjects. In their reports the

subjects pointed to uncertainty about the disease and its outcome, as well as the emerging disabilities which affected the meeting of need on a day to day or more long term basis. Bury's (1982) study also highlighted the disruption of social life and activity due to functional limitations and stigmatization.

An individual's ability to meet needs contributes in part to quality of life. The impact of R.A. on the general quality of life (QOL) has been addressed by Burckhardt (1985). The impact on the QOL was assessed through consideration of pain, functional impairment, as well as social and psychological factors. She hypothesized that psychological mediators, specifically positive self-esteem, internal control of health and perceived support and low negative attitude toward the illness, indirectly affected quality of life. Instruments used gathered data on severity of pain and impairment, quality of life, socioeconomic status, social network, perceived support, self esteem, negative attitude toward disease and internal control over health. The results indicated that those mediators contributed directly to a higher QOL. Interestingly the study found that the factors or characteristics which people use to define QOL are the same for healthy and disabled people. Individuals with arthritis were found to have lower life satisfaction scores. As a mediating variable, self esteem was found to account for 25% of variance. Those who had a belief in themselves as

efficient and friendly, rated their QOL as highly satisfactory. Higher degree of impairment was related to lower self esteem possibly due to an inability to do activities of daily living. Internal control over health contributed to 20% in variance with those who believed they had the power to make themselves well having a higher QOL score. Control is difficult to achieve in R.A. because of its unpredictable course. This was also related to the degree of impairment with those who were more impaired and older sensing a lower QOL. Negative attitude accounted for 15% with those who were depressed, angry, worried, frustrated, discouraged about the R.A. experiencing lower QOL. Pain contributed to increased negativity toward the disease. Older subjects were less negative toward the disease, perhaps being evidence of an increased acceptance of R.A. over time. Finally, perceived support contributed 10% to the variance in QOL. The presence of others for physical help and advice and socialization resulted in higher QOL, particularly if contact was frequent and there was interaction amongst network members. While older subjects tended to have denser support networks, they did not necessarily perceive increased support. This may be indicative of an unwillingness to solicit help. The study showed that psychological variables are important in mediating the affects of pain and functional impairment in R.A.

Psychosocial Impact of R.A.

The need to consider psychological aspects was also

voiced by Semple (1982) who noted that consideration had to be made of the effect that psychological adjustment might have on coping with the physical problems presented by the disease. Earlier studies questioned the possibility of a rheumatoid personality in which psychological factors existed prior to the onset of the disease (ie. rigid, insecure, angry) and indeed may have contributed to the onset of the disease (Moos, 1964; Moos & Solomon, 1964; Polley, Swenson & Steinhilber, 1970; Hoffman, 1974). This stance has since been refuted (Zeitlein, 1977; Spergel, Ehrlich & Glass, 1978). While individual personality traits must be considered, behaviours may be more indicative of psychological response to the course of illness producing what might be call a "chronic disease personality" (Spergel, Ehrlich & Glass, 1978, p.79). In their study of 46 individuals with R.A., Spergel et al (1978) did note a significant difference (statistics were not reported) between men and women with women appearing to be in greater emotional conflict than men and with women tending to deny their involvement and to minimize their symptoms. Differences also appeared in the family self variable with women more satisfied with the family self role than men. Spergel et al (1978) suggested the homemaker concept remained an important organizing life principle for women. This latter aspect was considered in a study by Reisine, Goodenow and Grady (1987) in assessing the impact of R.A. on the homemaker. They note that biologist Rene Dubos and others have maintained

that performance of accustomed role may be a critical aspect in the individual's defining the quality of life. Because of the nature of the disease involving progressive joint damage and destruction, achievement of functional activities including the social is often compromised. They note that previous studies have not satisfactorily operationalized dysfunction in social roles other than in paid work outside the home. Reisine, Goodenow and Grady's (1987) study considered 142 homemakers with R.A. on two dimensions: instrumental functions in meeting physical household needs and the nurturant function concerned with meeting expressive needs of the household. They found that the disease significantly limited function in both dimensions. Nonsignificant differences were found between women who worked outside the home as well and those who were not employed. Both groups assumed, "major responsibility for homemaking" (p.). They concluded that function in a variety of social roles needs to be considered if one intends to sensitively evaluate the effect of such a chronic disease on women.

Psychological Impact and Loss

As Semple (1982) has noted, although R.A. is primarily a physical disease it also has psychological, social and economic consequences. Psychological management is crucial to effective management and rehabilitation (Semple, 1982). Zeitlein (1977) sees the psychological, social and personal factors as important components in the task of "mourning"

which he views as necessary in learning to adjust to, accept and live with R.A. This includes learning to deal with the "disturbing subjective meaning of the illness and its manifestations" (Baum, 1982 p.352). He views successful mourning as a compromise with the individual forming a unified self image in which he/she is able to make a distinction between the self and the disability and to accept the self as a person with "somewhat limited physical capacity" (p.12). Zeitlein (1977) has noted the past emphasis in the literature on "negative personality traits" had detracted from the importance of "marshalling positive personality traits that enhance self esteem" (p.11) particularly, in light of the impact that decrease in functional ability can have on lowering self esteem. Part of the loss of self esteem may also be related to feelings of impotence, defectiveness and shame associated with having a painful, potentially disabling and deformity producing disease (Zeitlein, 1977; Semple, 1982). While disability and physical deformity may compound the readjustment problem, the majority of individuals with R.A. are not wholly disabled (Ehrlich, 1983). The disabilities present are rarely totally incapacitating; nevertheless, they tend to be viewed by the individual, family and majority of physicians as indicative of a "relatively hopeless diagnosis" (Ehrlich, 1983, p.29). As Ehrlich (1983) notes many have recovery or improvement potential which showed results in some degree of hopefulness. But because of "the

variation from the norm", psychological overtones put social function and integration at risk (Ehrlich, 1983). Thus while the psychology of the individual prior to onset must be considered, one must also be very cognizant of the implications of the disease affect. These effects have resulted in restricted activity, fear of being crippled, disillusionment with the health care system for having no cure or even effective treatment, constant pain in some degree, financial difficulties, family dysfunction and perhaps a general difficulty in coping with commonplace occurrences (Semple, 1982). Negative attitude, sense of loss and depression may be evident as adaptation to the condition. As Ehrlich (1983) noted, "for the disabled patient, loss of physical capacity for those responses that maintain and establish relationships and participation in the varieties of activities open to non-disabled persons may well be a major loss" (p.30).

This concept of loss was addressed in a comparative study of the impact of rheumatoid arthritis (R.A.) and osteoarthritis (O.A.) (Yelin, Lubeck, Holman & Epstein, 1987). From analysis of data gathered by log, diaries and interviews, Yelin et al determined that individuals with R.A. experience more losses in the every day domain of human activity than did the healthy controls in the study. Individuals with R.A. experienced losses in the performance of household chores, shopping, and errands as well as leisure activities. They

experienced losses in full or part time work as well as overtime (37%) and also in exercising and walking (41%). The latter is particularly important when one considers that regular exercise, geared to the individual's strengths and limitations is critical to the prescribed treatment regimen. There was a loss in ability to participate in religious activities (ie. attend church 22%; church business 14%; private prayers 4%). This is important when considering the role that faith might play in a positive attitude toward the disease or to the acceptance of it. Duration of time spent on activities was also affected to some extent, with those with R.A. spending more time than controls on shopping, errands and in personal care and hygiene.

A study by Meenan, Yelin, Nevitt and Epstein (1981) also found major losses in the areas of work, finances and family structure. Of the 245 subjects interviewed, a majority of workers were found to be totally disabled by the R.A. Of the 74% subjects who were employed when the disease began, 59% (106) were no longer working. There was a decreased ability to work and a consequent reduction in income. Furthermore, these respondents were earning less (up to 50%) of the income predicted for them had they not had R.A. Those with most severe forms of the disease and/or disease of longer duration were also likely to be more disabled and not working. Two work factors, self employment and workplace autonomy, played a part in decreasing the probability of disability. Age, sex,

race and education were found to have no significance in effecting work disability. The impact on the family was evident with divorce or separation being common. A reduction in income also tended to result in a change in residence, decrease in leisure activities and alteration in family members' roles from unemployment to employment in an effort to supplement lost income. The researches concluded that work disability appeared to be the most important sociomedical impact because of its association with income loss and psychosocial losses.

Ehrlich (1983) also tackles the issue of work and arthritis related disability. In citing the work of others he notes that R.A. "severely disables only 323 members of a population of 250,000" (p.31). He maintains that successful retention of work or return to work is related more to factors other than the disability. Individuals with R.A. tend to have a low level of absenteeism despite the physical limitations. Attitudes of employers and the insurance industry are perhaps more of a factor in limiting employment (Ehrlich, 1983). Work and social factors then, can play a part indirectly in increasing or decreasing the quality of life experienced by individuals with R.A.

For anyone affected with R.A., the longer the individual has the disease, the greater the likelihood of "undergoing debilitating changes" (Lambert, 1985 p.52). Difficulty in performing physical activities and functions will eventually

necessitate seeking assistance from others which may be reflected in a dependence of a greater or lesser degree. The inability to perform tasks also may result in frustration and depression, which is further compounded by the presence of pain which may be so overwhelming that it "dictates the afflicted woman's lifestyle" (Lambert, 1985, p.53). In her study of psychological well-being in women with R.A., Lambert (1985) found that dependence on others correlated with length of time with illness, difficulty in performing tasks and age. As pain and difficulty in performing tasks increased, psychological wellness decreased. The role of social support was also considered in Lambert's (1985) study because of previous studies which have indicated individuals with sufficient support have a lower incidence of somatic illness, have higher morale and a more positive state of mental health. Lambert's (1985) study found a negative correlation between age and tangible support suggesting that as the woman ages so too do her supports, thereby no longer being as available. Support is an important factor in learning to live with R.A. and to become self-sufficient in order to enhance psychological if not physical well-being.

Self Care As A Factor In Management

Effective management of R.A. ideally will result in positive health and well being. The management may be accomplished through effective self care, which is directed to meeting the health deviation self care requisites by seeking

professional help, using and undertaking treatment, accepting the condition and learning to live with it (Orem, 1985). As Ruffing-Rahal (1985, p.21) has noted, this entails a conception of healthiness which has as its epitome a "singular balancing of self-sufficiency and dependency" reflecting a "truce" in the perpetual struggle with "unpredictability and irreversibility", both of which are associated with R.A. Self-actualization and growth are possible in the midst of long term illness and may be achieved through acceptance of responsibility and a realistic appraisal of shortcomings in order to enable achievement and optimal function (Ruffing-Rahal, 1985). The ability to achieve not only enhances a sense of autonomy and control, but also helps to promote a sense of normality.

A part of the realistic acceptance of responsibility for self is the seeking out of necessary assistance to enable optional function, as is the case when a deficit in self care agency exists. The individual as self care agent would then turn to another care provider within the greater system, be it societal, health care or other. This seeking out can be complicated by the variety of perceptions about health and illness that prevail and which reflect different values, beliefs and experiences within society.

Society's Influence in Self Care

Society plays a key part for "all societies possess a body of belief about the nature of disease, its causation and

treatment, as well as health specialists or curers" (Logan & Hunt, 1978 p.149). Furthermore, societies "specify the conditions that make it legitimate for its members to seek the various kinds of human services that are provided. These conditions become the criteria that members of the society use in determining whether or not a human service can or should be used" (Orem, 1985). Societies may be further subdivided into different cultural or ethnic units which may reflect similar or differing criteria, based on values and beliefs.

In North America, these conditions or criteria are partly dictated by the acceptance of the biomedical model, with its rational base as the "foundation of contemporary, Western, scientific medicine" (Gillick, 1985). The etiology and course of illness is the focus. Not all members of society subscribe to the medical model as explanatory for disease and deviation from health. Health beliefs and practices of nonwestern peoples have been widely studied as indigenous or traditional healing systems (Kleinman, 1980) and ethnomedicine (Logan & Hunt, 1978). Also, as Gillick (1985) has suggested many other "common-sense" models exist in modern society such as organisms struggling against internal or external threats from malevolent forces or vitamin deficiency as an explanatory model for disease.

Therapeutic practices prescribed for any given disease may have socially cohesive results, thereby strengthening the social unit (Hughes 1978; Kleinman, 1980). Therapeutic

directive are intended not only for the patient, but often also for the group or selected members of the group. The group and individual are thus reintegrated around common social values and beliefs (Hughes, 1978).

As Hughes (1978) notes, "some rudimentary medical knowledge is an aspect of enculturation" in all societies. The knowledge required to deal with disease is specific and requires a practitioner or specialist. Western medicine reflects this readily in that there is a society of healers comprised of physicians, physiotherapists, nurses and others each with its own body of knowledge and practice. This has been further complicated by the increasing complexity of the health care system (Fagerhaugh, Strauss, Suczek, Wiener, 1980; Wiener, Fagerhaugh, Strauss & Suczek, 1982).

Not all individuals within any given society subscribe to a disease centred model. For some, health and wellness remain the focus and guide their actions (Ruffing-Rahal, 1985). Even in the midst of illness they may choose to exercise self responsibility and self care by seeking approaches which are less intrusive and have fewer unwanted side effects than those traditionally prescribed within the medical care model. A combination of approaches may be utilized to achieve a level of health or wellness (Clark, 1983; Ruffing-Rahal, 1985). As well as a person's values and beliefs about health, illness and appropriate interventions, other factors are important in achieving a holistic appreciation of the individual's actions

within a context. These would include the individual's gender, age, presence or absence of family, lifestyle choices, health state and availability of health care systems and resources.

Information and Self Care

One of the main resources which the individual, as potential self care agent, must access is that of information. In order to be able to perform effective self care, any individual would require pertinent information about the disease and its management (Orem, 1985; Rodnan & Schumacher, 1983).

A study by Price, Hillman, Toral and Newel (1983), addressing the public's perceptions and misperceptions of arthritis, indicated a clear need for appropriate information. 300 respondents from the general public were randomly selected and interviewed by telephone. Most reported a reliance on the mass media for information with T.V. and magazines noted as sources. Friends accounted for 51%, physicians 38%, and Arthritis Foundation 33%. Past studies cited by the researchers indicated a majority (80%) of individuals with arthritis wanted more information. The study found that 18% believed it could be cured thus making them vulnerable to false claims ("quackery"). Only 13% could name R.A. as one of the two major types. Over 40% believed they would eventually develop arthritis and if information was being consciously sought they would turn to a physician (62%), Arthritis

Foundation (42%) and library (13%). The mass media has a great potential to shape perceptions and establish a knowledge base about arthritis. The unproven remedies such as copper bracelets, vitamins, and bee venom were supported by at least 50% of the respondents. A second sample of diagnosed arthritics was selected to determine the actual incidence of utilization of alternate treatments. At least half of the sample had used some of this category of remedies. The sample with arthritis did not have as high a rate of use of unproven remedies as the general lay public. The researchers concluded that the sampled lay public was not well informed about arthritis.

Information about R.A. and its management may come from a variety of sources: popular literature; institutions associated with health care; or self help groups. A great variety of books have appeared on the market which either deal fully or in part with R.A., its effect and treatment (Stanway, 1980; Ellert, 1985).

Popular journals or newsmagazines remain a common source of information. The popular press such as the National Enquirer, an American tabloid with a tendency to sensationalistic reporting, can be responsible or essentially accurate in the dissemination of information (Ross, 1987; Ruehl, 1985; The National Enquirer, May, 1983, Dec 1983; Winnipeg Free Press, June 1985) concerning etiology, attitude and treatment. Other publications of the popular press can

contain irresponsible and misleading information (The Examiner, 1989; The Globe and Mail, 1987) with unrealistic claims being made. The Examiner is an American tabloid while The Globe and Mail is a Canadian conservative daily newspaper which at times has published advertisements concerning alternate treatments such as Chinese herbal medicines.

The health care system, represented by institutions and its members, often serves as the primary (both first and main) source of information for the individual. As Rodnan and Schumacher (1983) have indicated education needs to begin the moment the diagnosis has been made. This is supported by Price, et al (1983) who noted in a follow up study that arthritis patients who had received some education concerning R.A. did not reveal as high a rate of use of unproven remedies. This finding, combined with their original study cited earlier, indicated the "need for more and better quality public education on the problem of arthritis" (p.1020). As Ehrlich (1983), Levin (1978) and Rovers (1987) have noted, in order to get individuals to accept and practice the prescribed regimen, it is "not sufficient to merely educate the patient" (Ehrlich, 1983, p.32) but rather health providers need to have the patient/client involved in the planning of the care. In patient education, as commonly practised in institutions, the focus tends to be on what the health professional thinks is good for the patient, whereas in self care education the focus is on what the learner (patient/client) has perceived as needs

and goals (Levin, 1978). The individual may also be viewed as passive with the health professionals maintaining control. As Hagey and Buller (1983) have noted, learning takes place in a social and political context with recipients of care possibly being coerced into sharing the caregivers' beliefs. Levin (1978) has noted that self care tends to build on personal and lay practices and supplements them with medical-technical concepts and practices, reflective of mainstream Western medical culture. Self care education tends to use a more holistic and social approach, while patient education tends to focus more on individual personal health behaviour (Levin, 1978).

Self Help Groups and Self Care

The meeting of an individual's educational (learning) needs may be more readily met within a self-help group framework, which tends to offer both information and support. These groups, partly as a response for individuals to have self determination as well as to meet learning needs, have proliferated greatly in society in the past few decades (Trainor, 1982; Corbin, 1983; Gilbey, 1987). Health care needs are often fulfilled by self help groups and the "importance of self health often has been overlooked" (Corbin, 1983, p.10). The importance of social support in influencing matters of health has been documented (Eisenberg, 1979; Hiss, 1986; Hubbard, Muhlenkamp & Brown, 1984; Isom, 1982). Self help groups may help to foster effective self care by offering

support and by disseminating current, pertinent information about the condition and its management. This may take the form of a newsletter, thereby promoting a more solid knowledge basis upon which to build self care activities (Rovers, 1987). Also, information not wholly exclusive to the mainstream or conventional health care system may be offered and need not be contradictory, but may in fact be complementary (Corbin, 1983). Information has also been shared by trained lay instructors (Lorig, Lubeck, Kraines, Seleznick & Holman, 1985); and by health professionals serving as guest speakers (Gilbey, 1987). Participation by the health care worker may have the added benefit of the professional learning and developing insight (Gilbey, 1987).

Nursing and Self Care

Nursing can offer support by conveying pertinent, accurate and current information from a holistic perspective, while still allowing the individual to have some control in identifying self-care needs, goals and responsibilities (Joseph, 1980). The importance of self care and nursing's role in it, as well as nursing's incorporation of it in a variety of settings has been well documented in the literature (Kinlein, 1977; Anna, Christinsen, Hohon, Ord & Wells, 1978; Bromley, 1980; Mullin, 1980; Hanks, 1984; Moscovitz, 1984; Whetstone, 1987).

True fostering of self care entails a collaborative activity, which suggests joint, cooperative behaviour which is

directed at achievement of the same identified end. As Whetstone (1987) has noted, "current nursing theories stress this benefit of enlisting the patient's involvement in their own health care" (P.168). As Hiss (1986) has noted this necessitates a change in the traditional patient physician relationship to one of partnership in decision making in which the individual makes an informed choice. Effective self care then assumes decision making and problem solving skills and the role of self care education would be to encourage circumstances where these skills are nurtured and supported (Levin, 1978).

Decision Making

An inability or lack of desire to participate in decision making may be a reason for apparent adherence or non adherence to treatment or selection of certain aspects of self care over others. Preference for control over treatment decisions has been addressed in a study by Degner (1977). Although the study focused on adults with cancer, basic tenets apply to adults with R.A. As Degner has noted, "matching treatment approaches to preferences about the amount of control deemed in clinical decision making is a more rational response to consumerism than advocating increased control for everyone irrespective of preference" (p.1). The study used four patterns of control over treatment decision: provider controlled decision making; patient controlled decision making; family controlled decision making; jointly controlled

decision making. This model would readily apply in a consideration of individuals with R.A., and may be a way of determining why some individuals follow prescribed regimens and why some apparently do not.

Another reason why individuals may choose to follow or adhere to a different regimen other than the one suggested is because of a failure in the communication between the care provider and recipient (Price et al, 1983; Rovers, 1987). This may partly be due to an incongruity in views regarding importance of various aspects of treatments, with professionals underestimating the patients' desire for education about the disease (Potts, Weinberg & Brandt, 1984). In a study by Starfield, Steinwachs, Morris, Bause, Siebert and Westin (1979) patients reported more improvement of problems at follow up when both practitioner and patient mentioned the problem as requiring follow up, rather than when it had only been identified by the patient. This concept of incongruity leading to involuntary or inadvertent nonadherence was also addressed by Jette (1982).

Affective qualities could also positively or detrimentally affect the nature of the interaction and sought outcome behaviours. As indication of the breakdown in doctor-patient communication, Korsch, Gozzi and Francis (1968) address the perceived "lack of warmth and humanity in the available medical care". (p.855) Attention to patient's fears, ideas and expectations were considered to be critical. In an

Israeli study, Ben-Sira (1982) found that the inclination to judge medical treatment was partly done on the basis of satisfaction or dissatisfaction with the physician's affective behaviour. The perception of the affective behaviour was also to play a part in the choice of other treatment agents.

There are other perceptions which may also affect choice of and participation in treatment regimes. This could include availability, accessibility, acceptability and adaptability to own personal use of the treatment (Anyinam, 1987). A multitude of factors are involved in making a choice or choices related to personal health behaviours (Weinberg, Spiker, Ingersoll & Hoersting (1982). Severe health deviation may act as a precipitating factor in a willingness to take risks in order to achieve a hypothetical cure for the R.A. (Thompson, 1986). In an American study, up to 27% of the 247 subjects with R.A. were willing to take the maximal acceptable risk (death) to achieve a cure (Thompson, 1986). Most were willing to pay to achieve a cure, with a mean of 22% of household income being given. Pain was most associated with maximal risk while impaired activities of daily living were associated with willingness to pay. Thus desperation may drive individuals to actions which may not be most beneficial to health care. It must be noted that this was an American study where health care is not as comprehensive or universally available to all and where individuals are required to pay for many services.

Finally, individuals with R.A. may make their choices based on belief systems (Weinberg et al, 1982; Guccione, 1982; Falvo & Achalu, 1983; Chalmers, 1984; Lorig, Cox, Cuevas, Kraines, & Britton, 1984). As Chalmers (1984) notes, dissimilar beliefs may be held by health care providers and health care recipients about R.A. He acknowledges that "concordances of the viewpoints of patients and health care providers modifies outcomes, compliancies and patient satisfaction" (p.1).

This diversity may serve as an impediment to effective communication which is the essence of a helping relationship (Spradley, 1985). Communication facilitates information gathering, identifying of values, beliefs, needs and conveying of the information needed by the individual (Hagey & Buller, 1983). Communication and the helping relationships are facilitated by the use of interpersonal skills such as displaying respect, caring and empathy (Spradley, 1985; Rovers, 1987). As Hodson (1967) has noted, a climate in which rapport and trust is established is necessary. There is evidence that indicates the client/patient needs to like the health care professional in order to be able to feel comfortable about sharing information (Rovers, 1987). In citing other studies, Price et al (1983) noted that 35% of arthritic individuals surveyed had not understood their doctor's explanations and 80% had wanted more information about their condition. A lack of clarity between the intended

and interpreted message will result in discrepancy which will, in turn, affect the desired outcome of the interaction (Gerrard, Boniface & Love, 1980; Rovers, 1987). This is particularly true when individuals from another culture interact with health care professionals. Definitions of health and illness and therefore means of treating them may also vary with beliefs. It is the health care provider's responsibility to understand the messages (and hence concerns) from the individual's perspective (Haynes, Taylor & Sachett, 1979). Falvo and Achalu (1983) noted that marked differences of perceptions between physicians and refugees may arise with regard to health status and health need. They noted that amongst Indochinese people, where traditional belief systems influence health belief, an eclectic approach to health care may be taken which combines modern procedures as well as native and home cures. This complementarity has also been advocated by others (Stanway, 1987). The issue of clients using a combination of alternate treatment methods and prescribed treatments has been addressed by Guccione in considering the ethical dilemma faced by health care providers. He acknowledges the right to self determination by individuals, but also recognizes the obligation health care professionals face in protecting individuals from harm. This stance by the author, while reflecting concern, also reflects a paternalistic view which suggests the patient must be saved from himself. The patient has the right to make what the

professional might consider to be a mistake. Ultimately, it is the perceptions of the patients about treatment methods and providers which will decide their choice, not the providers' beliefs about the recipients' perceptions (Lorig, Cox, Cuevas, Kraines & Britton, 1984).

Conventionally Prescribed Treatment

As has been noted earlier, the aim of prescribed treatment is to relieve pain, reduce inflammation, minimize the affects of the R.A. and maintain joint function (Rodnan & Schumacher, 1983). Conventional, prescribed treatment traditionally has included a combination of a variety of medications, rest and exercise as well as education about the disease, its course and management (Rodnan & Schumacher, 1983; Porter, 1984). As Hart (1976) notes, "it is really only since the second World War that rheumatoid arthritis and its treatments have received the recognition they deserve by the medical profession as a whole" (p.765). Simple analgesics (such as acetaminophen with/without Codeine) and the non-steroidal anti-inflammatory drugs (NSAIDS) (such as Naprosyn, Orudis, Indocid, Salicylates) are the drugs most commonly used in the treatment of R.A. (O'Duffy, 1980; Rodnan & Schumacher, 1983; Hill, 1984; Baum, Kennedy, & Forbes, 1985; Hennig & Burrows, 1986). Their primary function is to reduce pain and inflammation respectively (Hill, 1984). Unfortunately potentially dangerous side effects are associated with many of the drugs in these groups (Hill, 1984;

Hennig & Burrows, 1986). The corticosteroids were once "heralded as a major break through in the treatment of rheumatoid arthritis" (Hill, 1984, p.905), also have undesirable side effects (Rodnan & Schumacher, 1983; Hill, 1984; Porter, 1984; Hennig & Burrows, 1986). Its use is primarily restricted to the treatment of unremitting disease (Rodnan & Schumacher, 1983; Hill, 1984; Bertouch, Roberts-Thomson, Smith, Woodruff, Brooks & Bradley, 1986) or to intra articular injections as an adjunct to other prescribed therapies (Rodnan & Schumacher, 1983; Hill, 1984; Hennig & Burrows, 1986).

Other drugs and treatments of a somewhat marginal nature have been tried in conjunction with salicylate or NSAIDS and may include the antimalarials, gold (Cryotherapy), penicillamine, immunosuppressives (e.g. methotrexate) or radiotherapy (Rodnan & Schumacher, 1983; Hill, 1984).

While research has focused on finding more effective drugs for treatment, nevertheless, as O'Duffy (1980) has noted, most individuals with R.A. will be taking therapeutic doses of nonsteroidal antiinflammatories or salicylates. Salicylates remain the mainstay of the therapeutic regimen (Rodnan & Schumacher, 1983). Interestingly, as Goodwin and Goodwin (1981) have noted its efficacy as a treatment in R.A. was slow to be recognized by the medical establishment.

Invasive interventions in the form of surgery may also be a method of treatment, particularly for the relief of pain

(Rodnan & Schumacher, 1983). Surgery for R.A. has a fairly recent history (Vainio, 1983). The literature has addressed the variety of surgeries which may be performed and the benefits which have resulted (Vainio; Yamamuro, 1985; Wordsworth, Shakespeare & Mowat, 1985; Gill, 1987).

The use of physical therapies can play a major part in the treatment and management of R.A. (Rodnan & Schumacher, 1983). The aim of physiotherapy is to make the individual as "independent and confident as possible" (Bretherick, 1984, p.922). In conjunction with analgesics and anti inflammatory, treatments such as ice, massage, ultrasound, heat, hydrotherapy and exercise may be instituted (Bretherick, 1984). In order to reduce the risk of injury to the joint and to maintain mobility and independence, splints may also be of use (Bretherick, 1984; Peasnell, 1984). Splint use and factors affecting compliance among 36 patients were studied by Nicholas, Gruen, Weiner, Crawshaw and Taylor, (1982). Their findings suggested that patients wear them but not frequently enough. Of interest, is the fact that they stated that they did not wear them "for pain", but they reported both relief and support when the splint was worn. Nicholas, Gruen, Weiner, Crawshaw and Taylor (1982) felt that this reflected an educational problem, against which a vigorous education effort should be directed in order that the individual can understand that splint wearing is an "acceptable and successful method of treating inflamed joints" in R.A. (p.94).

A team approach consisting of physiotherapists, physicians, nurses, occupational therapists, pharmacists, social workers, dietitians, and counsellors is advocated in the management of R.A. (Rodnan & Schumacher, 1983). The coordinated team approach, using a variety of allied health professionals is advocated by Feinberg and Brandt (1984) who concluded that regular, ongoing involvement of coordinated health professional team in the management of individuals with R.A. might be more beneficial than "episodic" care.

The team of allied professionals also plays a key role in the education of the patient and family. The nurse, as a professional who is in contact with the hospitalized patient 24 hours a day, is a key component of the team (LeGallez, 1984; Porter, 1984). Patient education may be conducted as in-patient classes, out-patient sessions or special one-to-one out patient education in the community by nurses specially trained in rheumatology. A prospective analysis of patient education for individuals with R.A. was conducted by Parker, Singesen, Hewett, Walker, Hazelwood, Hall, Halsten and Rodon (1984). Using twenty two males assigned randomly to either an inpatient medical care group which also received a formal patient education program or a group perceiving only the inpatient medical care, they found that while education was effective for increasing rheumatoid arthritis knowledge, topics such as disease process and joint protection might actually adversely affect how patients view their physical

capacities and interpret (or perceive) their pain. Parker et al (1984) believed that patients "place their own cognitive interpretation on the education process and that such interpretations are not always those which are intended by the educators" (p.774). An article by Cave (1984) addressed a nurse-led support group which was formed to promote information exchange, ventilation of feelings and mutual encouragement. It was found that one of the important functions of the group was to lower the uncertainty over medications and treatments. A similar community based project was addressed by Lorig (1986) in which a 12 hour community based course was established which had several attributes that differentiated it from most patient education. It was community based in accessible, convenient locations; it emphasized self help; it used lay instructors; it had materials which are inexpensive and simple and it was carefully evaluated. As Porter (1984) notes, it is "important not to underestimate the significance of the patient education movement" for it reflects a changing relationship between provider and recipient (p.vii). Patient education, in whatever form, reflects the commitment of many people, lay and professional alike, who "believe patient education yields more humane care and is also effective as treatment modality" (Porter, 1984, p.viii).

Alternate Treatment Modalities

A variety of alternate modalities, reflecting methods not

conventionally prescribed in the treatment of R.A. may be turned to. These therapeutics generally represent medicinal and body-mind categories, such as herbalism, massage, chiropractic, therapeutic touch, yoga, acupuncture, acupressure, and transcendental meditation by way of example (Stanway, 1987). These tend to reflect natural, non-invasive means to promote well-being or reduce the effects of disease (Rautavaara, 1980; White, 1988; Stuart & Vines, 1988). Use of alternate modalities may also reflect a more holistic approach to health and illness (Baker, 1985; Stanway, 1987; Williams, 1988). As Williams (1988) has noted wholeness is facilitated by helping healing to occur through the integrity of mind, body, spirit and the environment.

Alternative treatments have tended to be viewed as "quackery" in the past. Quackery has been defined as that which is advertised as curing a particular ailment or disease while the real aim is to take advantage of the public (Berry, 1986; Hawley, 1984; Lynch, 1976). Differentiation in Western culture has generally been claimed to be on the basis of validation by science (Hawley, 1984).

Interest in holistic health has not only increased among the general population, but also among health care professionals (Goldstein, Jaffe & Sutherland, 1986; Brallier, 1988). In a study by Goldstein, Jaffe and Sutherland, (1986) physician respondents were cited as using a range of holistic techniques in their practice. Of the 58 surveyed, 6 reported

using 2-3 while 2 reported using a maximum of 20 different holistic techniques. The most frequently cited examples were nutritional medicine (86%), psychological counselling (81%), meditation/relaxation (75%), laying on of hands (72%), guided imagery (70%), herbal medicine (50%), hypnosis (48%), acupressure and manipulation (each 43%), biofeedback (40%), and acupuncture (32%). Reflexology was cited only 17% of the time. Perhaps most surprising, in that it was cited as a holistic technique, was patient education, a method used 93% of the time (n=54). They concluded that the conference attendees had used techniques of healing that "most physicians would not normally consider justified". (p.8)

The use of similar alternate modalities was noted by Kronenfeld and Wasner (1982) in their study of the use of unorthodox therapies and marginal practitioners. Of the 98 respondents 61% were individuals with R.A. Almost all of the respondents (94%) had tried some unorthodox remedy/practitioner, with a few having used as many as 13 remedies or practitioners. Categories of treatment reported included topical lotions applied locally (e.g. alcohol, brake and motor fluid, cod liver oil, olive oil ...) cited by 80%; specific diets or food cited by 54%; vitamins were cited by 24.5% with jewellery (eg. copper bracelet) and trips to climates or locations attributed to helping R.A., receiving 37.8% and 12% respectively. Also, 36% of the respondents had visited an unorthodox healer (faith healer, homeopath,

chiropractor). The majority (83%) had sought help after seeking assistance from a physician. No significance was found between age, sex, race, education, income, disease duration and usage. They concluded that folk medicine practice did exist and that examination of disease treatment from the lay perspective should be done. Further studies needed to be done which focused less on rural population where folk beliefs tend to be stronger. While their study found no statistical significance between education, income and unorthodox therapy use, they felt that ethnic, religious and possibly income variables may play a part. Cosmopolitan people, those living in urban areas, tended to seek orthodox therapy, perhaps reflecting a stronger acceptance of the medical model.

Use of herbs to treat ailments is one of the most commonly identified alternate methods (Kronenfeld & Wasner, 1982; Goldstein, Jaffe & Sutherland, 1987). Stanway (1987) notes herbalism, as the use of plants for healing, "is undoubtedly the world's oldest and most comprehensive therapy" (p.160). As Stanway has suggested, unlike some synthetics, they "have advantage of rapidly returning the body to a state of health without exhausting and damaging side-effects" (p.160). While benefits may be achieved, use of herbs is not without some danger.

Combining a prescribed conventional treatment with a natural medicinal remedy in which the ingredients are known

may be less hazardous than the use of a herbal remedy in which the active ingredients are not known. Concerns have been raised about specific drugs imported from the Far East in which the ingredients were unknown (Forster, Calverley, Hubbal & McConkey, 1979; Offerhaus & Dukes, 1979). Consideration must be given by health professionals because the dramatic results achieved might prompt individuals to take the drug for alleviation of symptoms (Newton, 1979).

Other herbs which have been emphasized in the treatment of arthritis include wild thyme, kelp, alum seed and bogbean (Stanway, 1987). These have not only anti-rheumatic properties but also may have diuretic or calming effects.

Humans have had a long relationship with plants over the centuries (Kaslof, 1980). In North America, the aboriginal peoples Natives have had a history of plant use for healing and promoting health (Turner, Bouchard & Kennedy, 1980; Walker, 1984). As Stuart (1987) has noted, "The study of herbs has only recently begun to lose its association with quack medicine and become part of the return to a more natural way of life" (p.7). Current research continues to reveal "medicinal properties in a variety of common plants" with promise of treatment for specific conditions being indicated (Kaslof, 1980, p.268). Furthermore, herbal medicine "attempts to treat the patient as a whole, rather than the condition in isolation" (Stuart, 1987, p.54). Nevertheless, while benefits may be the result, difficulties remain in examining, testing

and standardizing herbal preparations (Stuart, 1987).

Other alternate modalities cited have included nutrition or diet therapy and fish oil usage. The role of diet in disease and wellness has been well publicized (Bland, 1960; Hastings, Fadiman, Gordon, 1980), with support for the use of a balanced, nutritious diet. In a study by Panush, Carter, Katz, Kowsari, Longley and Finnie (1983) diet therapy for R.A. was systematically examined. The effect of fasting and possible food allergic response had been indicated in other studies. A controlled, double blind study was conducted over 10 weeks to determine the effect of a specific diet on patients with R.A. Results did not suggest any significant differences between patients on the experimental diet and those on the control, although two subjects on the special diet improved notably. This might lend support to possible benefits for certain individuals through dietary manipulation.

In addressing "Diet in the treatment of rheumatoid arthritis", Ziff (1983) supports the work of Panush et al (1983). The methodology and findings were essentially supported. Although there were no significant findings, Ziff comments that the subjects with arthritis were well motivated to stay on the diet because of high natural interest in the possible role of diet.

Ziff (1983) questioned the possibility of bias and actual compliance of the subjects because the study was done on an outpatient basis. Hospitalization would not only be costly

and impractical but might produce the confounding variable of rest as the beneficial component (Ziff, 1983). He supported the suggestion that diet may affect inflammation as seen in arthritis. His support was based on a number of studies which looked at the importance of fats, particularly the polyunsaturated fatty acid, linoleic acid, which has been shown in clinical studies to affect prostaglandin formation and consequently, inflammation by reducing it. He noted that the natural remedy, Evening Primrose oil is rich in linoleic acid. Ziff (1983) advocated further study of diet and the link that it might have to intermediary metabolism, immunity and chronic inflammation. Further study had been conducted in the area by Morrow and Levy (1983) in which they found that the type of fat given could influence the levels of specific autoantibodies. They concluded that low fat diet enhanced natural killer cells activity and recommended that therapy which involved reduced fat diet in human autoimmune disease should be investigated further.

Research conducted by Helliwell, Batstones, Coombes and Moody (1983) on the nutritional status of individuals with R.A. determined that the diets were deficient in the nutrient folic acid and zinc. Their findings further suggested that R.A. is associated with impaired nutritional states. Perhaps more important is their recommendations that R.A. and diet be critically examined in order to give the patient, clear cut answers. Individual arthritics who are determined and

motivated might well attempt long-term dietary therapies that could exacerbate existing nutritional deficiencies which in turn could further compromise immune status.

Fish oils, particularly cod liver oil, have been addressed in the treatment of R.A. (Bald, 1960; Kronenfeld & Wasner, 1982). In a 1987 study of fish-oil fatty acids in the individual with active R.A., Kremer, Jubiz, Michalek, Rynes, Bartholomew et al (1987) concluded that fish oil ingestion did result in alleviation of active R.A. They had conducted a double-blind, controlled study of 33 patients to determine the efficiency of fish-oil supplements. The subjects received prescribed treatment consisting of NSAID, slow acting antirheumatic drugs and prednisone. The two experimental groups received fish oil supplement. This could be considered to be an adjunct or complementary therapy. Two other groups received placebos. A fish oil component (EPA) is associated with inhibition of the formation of prostaglandins and leukotrienes. Fish oils were more efficacious than placebo in producing measurable improvement in number of tender joints and onset of time for fatigue. Interestingly the effect of the oil persisted beyond 4 weeks. They concluded length of time on the supplement is important and recommended further studies to determine mechanisms of action, optimal dose and duration of action.

In the past few decades nursing has increasingly recognized that there are many ways of achieving health which

go beyond treatment of the physical deviation and the body - mind duality (Lubkin, 1986; Williams, 1988). This is reflected in dedication of an entire issue of Holistic Nursing Practice to what may be considered as mostly alternate treatment modalities. Topics such as relaxation, biofeedback, guided imagery, use of storytelling, humour and animals as well as therapeutic massage, shiatsu and pain and stress management are addressed. Some of these as well as chiropractic, homeopathy, naturopathy, yoga, transcendental meditation, Transcutaneous Electrical Nerve stimulation (TENS), and therapeutic touch are addressed as common or popular treatment modalities to which individuals may turn to obtain relief or achieve a higher level of wellness (Lubkin, 1986).

Scientific research has and is being conducted to determine the efficacy of many of the above therapies. Orsham (1988), in addressing pain and stress management considers current theories. The mind-body connection has been acknowledged with research in the area of psychoimmunology as well as psychoneurophysiology with the immune system seen as a protector and the stress as a reducer of certain immunoglobulins or immune competent cells (Locke, Kraus, Leserman, Hurst, Heisel & Williams, 1984; Orsham, 1988). Immunomodulators, which are opium like substances, can also be activated as endorphin or enkephalin which help to combat chronic pain (Orsham, 1988). This also provides a sense of

control for the individual and those suffering with a chronic diseases frequently feel a loss of control, power and feel helplessness because of the disease effect (Anderson & Bauwens, 1981; Miller, 1983; Lubkin, 1986). A sense of control not only helps to reduce the stress, but also helps to increase the individuals sense of self esteem (Orsham, 1988).

This activation of mind and body to help the individual heal the self is also an important component of biofeedback therapy, therapeutic touch and guided imagery therapy. Biofeedback is a recent phenonema having been developed in the mid 1960's with a tremendous increase seen in articles published in medical journals concerning this modality (Brallier, 1988). Biofeedback is now used effectively in a variety of health care settings and is a "proven and valuable adjunct to many treatments, especially when combined with other approaches" (Lubkin, 1986, p.299).

Hypnotherapy, meditation and relaxation have also been used (Stanway, 1987; Titlebaum, 1988). As Stanway notes, the "unconscious can play an extraordinary part in healing body and mind" and in trying to put the individual in touch with his/her "own powerful associations to relaxation" (p.312). Relaxation, as a therapeutic technique has been incorporated increasingly into treatment and prevention programs and has been associated with improved physiologic response in terms of lowered heart rate, blood pressure and metabolism, thereby bringing the body into a more balanced state (Titlebaum,

1988). The role of tension and anxiety in pain has been documented (McCaffery, 1983). Therefore that which can reduce them would be a benefit particularly to someone with chronic pain. Relaxation is also associated closely with meditation techniques (Titlebaum, 1988). As well as achieving personal benefits, meditation, particularly in the form of Transcendental Meditation (T.M.) may result in more practical, measurable benefits. In a five year study of 2000 participants in a T.M. program, Orme-Johnson (1987) found that the T.M. group had lower medical utilization rate in all categories studied. The T.M. group had 53.3% fewer inpatient admissions per 1000 and 44.4% fewer outpatient visits per 1000. Also, admissions were lower for major medical treatment categories. Unfortunately the rheumatic disease were not reported upon separately. The author concluded that T.M. was a "promising technology of health enhancement to prevent disease and to reduce medical care costs" (p.505).

Promise has also been shown for the therapeutics of guided imagery with scientific literature and nursing profession both investigating ways that guided imagery can be used to reduce stress, pain and alter disease course and generally improve health seeking behaviours (Vines, 1988). The technique is based on the belief that mind and body are "inextricably linked through images, which integrate psychologic, cognitive, affective and behavioural processes in the person" (Mast, 1986). As Achterberg (1985) notes it is

the "communication mechanism between perception, emotions and bodily change" (p.4) and as "a major cause of both health and sickness", it is also the "world's oldest and greatest healing resource" (p.4). It is a technique used for centuries, linked to shamans and medical practitioners alike (Achterberg, 1985). She maintains it is an integral part of health care, for "every interaction with health care personnel every diagnosis and treatment, create some kind of image in the patient's mind" (p.8). In turn, these images have the potential to alter the course of the disease. She supports the use of scientific method to investigate the therapeutic in an effort to establish "accurate, applicable, valid information which can be used in a productive sense of health" (p.8). In a review of studies which address therapeutic imagery, Mast (1986) found that there was not conclusive evidence for its effectiveness. She suggested further research particularly by nursing because "nursing models based on assumptions of ongoing interaction between the mind, the body and the environment provide conceptual frameworks from which imagery research could take place" (p.120).

Nursing has played a major role in the development of therapeutic touch as a healing modality (Krieger, Peper & Ancoli, 1979). Its basic tenet is that the ill individual, who is in a less than optimal energy state, can benefit by the excess energy present in all humans normally, which the therapeutic agent, as healer, has (Krieger et al, 1979). The

end result is a repatterning of the ill individual's energy level to a state that is comparable to that of the healer. Krieger et al. (1979) acknowledge it may well be "placebo" effect, but the benefit is achieved with the individual reporting feeling better. As Lubkin (1986) notes, "the placebo effect occurs when a subject feels better just because he or she took a pill, received a special bath or massage, or the like, not because the treatment actually had any pharmacologic or physiologic effect..." (p.293). The client's belief influences the physiologic impact. Therapeutic touch techniques have been used by others with positive effect (Macrae, 1979). Therapeutic massage in its many forms may also produce the same beneficial end result (White, 1988). The important point to note is that the use of hands as a therapeutic tool is traditional and universal, with much focus having been lost in the modern age of science and technology. The above is not intended to be a fully comprehensive review of all possible alternate modalities, but has been presented in an effort to convey the variety of measures which may be considered as a means to manage the arthritis condition.

In summary, this review of the literature has demonstrated the potential impact of the disease, rheumatoid arthritis. As well the discussion has noted the roles of society, self help groups and nursing in the consideration of self care as a factor in management. Decision making and

communication are addressed. Also considered was a selected variety of conventionally prescribed or alternate treatment modalities. In conclusion, the use of treatment modalities is a very individual action which has inherent in it the individual's feelings, perceptions, knowledge, past experiences as well as the context of the social and current situations.

Chapter IV

METHODOLOGY

Introduction

This exploratory study was conducted to determine the perceptions of adults concerning conventional and alternate treatment modalities in the management of Rheumatoid Arthritis. Judgement of the individual's beliefs and actions was not a purpose of the study. As an exploratory study, it isolated factors which reflected arthritics' perceptions of their experience with R.A. and the perceived efficacy of conventional and alternate treatment modalities in the self care and management of R.A. Within this qualitative paradigm data were collected using an open ended question interview format. Limited data is available on the perceptions and use of alternate modalities in the management of R.A. An exploratory study is conducive to generating more extensive data in this area. The research design consisted of sample selection from the membership of an Arthritis Self Help Group. Data was gathered through a single taped interview session in which an instrument in which an interview format consisting of open-ended questions developed by the researcher was used. Informed consent was sought from each participant prior to interview commencement. Data on sociodemographics and the experience with R.A. and its treatment were sought. A journal was maintained in which was recorded data relevant to each interview session. Interviews were transcribed and content

analysis was done.

Sample

The sample was derived from a population consisting of adults with R.A. living within the limits of the city of Winnipeg. A subset of the population was used as the target population for the study. The target respondent population used was the Arthritis Self Help Group which is ostensibly independent of formal health care agencies. The group has a Board of Directors as well as an Executive. The Arthritis Self Help Group had a total membership of approximately 200 members at the time of the study (personal Communication by the Chairperson, Board of Directors).

Specific criteria were used to determine participation in the study. Inclusion criteria consisted of the following:

The individual will:

- 1) be age 20 to 65 years (flexibility was allowed for the upper age criterion)
- 2) have had a formal diagnosis of R.A. made by a physician
- 3) have had some education/teaching about R.A. provided by a member of a health care agency
- 4) have had the diseases for one year or longer.
- 5) not be currently hospitalized or due to be hospitalized during the period of the study.
- 6) live within the city limits
- 7) have a telephone.

Non-probability (non random) sampling was used. Because of the exploratory nature of the study, the number of subjects sought was limited to a minimum of ten and a maximum of twenty. (A final sample of N=17 was obtained). As Roberts and Burke (1989) have noted, the extent of error due to sampling is an unknown and should therefore "be conservatively estimated to be high" (p.225). They also note that there has been a trend toward sample size of 15 to 20 or even 30 subjects in qualitative studies, for "sample size smaller than this make it more likely that the meanings are idiosyncratic and furthermore make it difficult to observe the identity of subjects as is required in most ethical consent forms" (p.225).

Respondents met the inclusion criteria, with two (n=2) beyond 65 years of age. Inclusion was allowed because both respondents felt that they would be able to recall events and experiences pertinent to the study.

Subject (Respondent) Recruitment

Upon receipt of approval by the Ethical Review Committee of the School of Nursing, University of Manitoba, The Board of Directors and the Executive were approached in order to gain permission for access to the Arthritis Self Help Group membership (Appendix B). The investigator received permission to attend the Board/Executive meeting at which time the study was explained and questions answered. A modification had to be made in the original plan to approach the membership at the

subsequent general meeting at which time an introduction to potential subjects would have been made (Appendix C). An insert describing the study and seeking volunteers was inserted in the Self Help Group newsletter due for distribution prior to the workshop. This was prepared and submitted to the newsletter editor (Appendix D). A designated member of the Executive then provided the investigator with the list of volunteers for the study. The investigator had no direct contact with the membership in soliciting participation in the study. This was seen as advantageous because of the reduction of potential coercion resulting from face-to-face contact. The investigator was provided with a list of twenty-one (21) names of potential subjects who showed an interest in participating.

Contact by telephone was made with all but two individuals. Two more were eliminated. One did not meet the criterion of having R.A., but rather had Osteoarthritis. The other individual, whose arthritis was in a quiescent state, doubted an ability to recall past experiences accurately or satisfactorily. It was mutually agreed that they would not participate. For the remaining 17 subjects a similar procedure of recruitment was utilized.

Having received indication of a willingness to participate, the investigator made a contact call, introduced herself, (Appendix E) and offered an explanation of the purpose of the study (Appendix F) which reiterated inclusion

criteria as well as stressing that judgement of the individual's beliefs and actions was not the purpose of the study. The method of data gathering and anticipated time for the interview were addressed. The offer was also made to have the Explanation of the Study and the Consent (Appendix F and G) mailed to those who wished it. All potential subjects contacted agreed to participate and it was arranged that the consent form was to be signed immediately prior to the interview commencing. Ethical consideration addressing anonymity, confidentiality and the right to withdraw at any time were also stressed. A time, date and location convenient to the subject for the purpose of data gathering was established.

Ethical Considerations

The protection of individual human subject was maintained though the use of informed consent seeking voluntary participation. All individuals who volunteered were provided with a verbal (by telephone) and written explanation of the consent form and study (Appendix F and G). Every attempt was made to reduce any potential risks related to the interview.

Confidentiality and anonymity were emphasized. Participants were assured that only the investigator would know the identity of the individual. Names were not used on the tape. Respondents and their corresponding taped interviews were identified by a numerical code only. Information matching the participant's identity with the

assigned code was available only to the investigator and was kept in a secure place. At the conclusion of the study, the tapes were erased. Assistance was sought (with advisor approval) to transcribe six interviews. The individuals transcribing were requested to maintain confidentiality.

Few or no risks were encountered in interviewing the individuals. Questions had been formulated with the view to reducing stress. By being open-ended they allowed the subject to determine the degree of elaboration in a topic area. When signs of distress did appear during an interview, the investigator promptly refrained from any further questioning and proceeded only after the participant indicated a willingness to do so. Potential risk was involved in the relative immobility of the participant during the interview. Prior to consent being obtained each participant was informed that time commitment involved could range from a minimum of one hour to a maximum of two and a half hours for the actual taped interview. Each respondent was informed that short breaks could be taken as necessary or if the individual felt that they had much they wished to share a second interview could also have been scheduled. (None chose to act on this latter option). The choice of the respondent's home as the site for the interview facilitated a freer moving about for the respondent.

While there were no direct risks involved neither were there any direct benefits to the participants of the study.

The interview did not create distress of any kind and might have been considered beneficial in that the participants might have felt that they were performing a worthwhile service in assisting with the study.

Determination of Rigor

Determining rigor in a study is important for as LeCompte and Goetz (1982) have noted "regardless of the discipline or methods used for data collection and analysis, all scientific ways of knowing strive for authentic results. In all fields that engage in scientific inquiry, reliability and validity of findings are important" (p.31). Qualitative methods have been criticized in the past for failing to pass tests of rigor in the areas of validity, reliability and objectivity all of which are "criteria of adequacy or rigor in scientific research" (Sandelowski, 1986, p.27).

Validity refers to relevance and whether the instrument actually measures what it claims to measure (Wilson, 1985). Face validity (Bush, 1985) was assessed by giving the interview guide to colleagues with graduate preparation and expertise in the area. Comments received did not indicate any difficulty in interpreting the questions or in relating them to the problem statement or purpose of the study. Content validity which is obtained by experts in the field was assessed by pilot testing the instrument with two adults with R.A. who met the criteria, but were not participating in the study. During testing, the questions put

forth by the investigator elicited the area of discussion sought by the question, although with varying depth due to the nature of each test respondent's individual experience. The responses reflected variables and concepts found in reviewing literature relevant to the problem. Thus judgement by experts and validation from the literature and pilot testing offered support for face and content validity.

Threats to internal validity were acknowledged as potential problems. These include observer effects (which may also reflect psychology of the respondent), involuntary error and spurious conclusions. As Field and Morse (1985) have noted "when a new member is introduced into a interaction it can be anticipated that the nature of the interaction will change" (p.120). The course of the initial telephone contact with the potential respondent sought to convey a non-threatening approach, and make a demonstration of interest in maintaining the participant's welfare (physical and psychological) during the interview. The initial period of the actual interview was used to establish comfort and rapport by reviewing the purpose of the study, obtaining consent and gathering sociodemographic data without the use of an audio recorder. As Lecompte and Goetz (1982) note "the observer's presence on the nature of the data gathered must be considered" (p.46). This was counteracted to an extent by the keeping of field notes and notation during the analysis and coding process which drew attention to observer bias or loss

of investigator objectivity. While entanglement may be a problem, efforts to assume neutrality may result in detachment which ultimately could destroy rapport (LeCompte & Goetz, 1982). Because of a single, limited contact with each subject entanglement was not a problem.

The psychology of the respondent was not found to provide a threat to internal validity. Threat might have resulted from a lack of willingness to work hard enough to retrieve information from memory to organize it effectively or from a lack of willingness to trust the investigator. Throughout each interview, the investigator tried to allow sufficient time for questions to be answered and attempted to pose questions which sought specific, definite details about past events. Also, the investigator attempted to provide a nonthreatening, non judgemental manner and response throughout. It was an underlying assumption that participants told the truth and recalled to the best of their ability. Involuntary error might have been due to a subject's inability to provide desired information due to a "lack of information, disorientation, memory loss or fatigue" (Chadwick, Bahr & Albrecht, 1984 p.110). To avoid this, questions were rephrased as necessary. The researcher was alert to signs of fatigue, discomfort or distress.

Spurious conclusions are the final threat to internal validity address by LeCompte and Goetz (1982). Consideration of this alerts the investigator "to resist

assuming relationships where there may be none or assuming nonrelationships where they may be obscured" (p.49). To counteract this they recommended that "all plausible causes are delineated by examination of collected data and through discussions with informants" (p.50). Throughout each interview, attempts were made to summarize, briefly, presented information for verification by the respondent. Also, if data indicated a potential code or category (such as risk/benefit factor) then this was put to the respondent for validation or rejection.

Threats to external validity also need to be considered. External validity refers to the ability to generalize beyond the sample that was used for the study (Bush, 1985). Threats to validity may come from population validity problems or pretest sensitization (Wilson, 1985). Population validity suggests that generalization can be made from the "actual sample to all possible sample members and likewise to the total population of interest to the investigator" (Wilson, 1985, p.147). Efforts were made to define the accessible population as broadly as possible to allow any member of the Self Help Group to be able to participate.

Because of the inclusion of the item in the newsletter seeking volunteers for the study, all members had an equal opportunity to volunteer. Volunteer bias may have resulted. Bias is defined as "any influence that produces a distortion in the result of a study" (Polit & Hungler, 1987 p.526).

Volunteers may have been representative of a particular perspective or experience base not shared by other members of the Self Help Group or of individuals who are not Self Help Group members. Pretest sensitization was reduced because the two individuals pretested were excluded from participating in the study.

Reliability must also be considered. Reliability refers to the replicability of scientific findings (LeCompte & Goetz, 1982). It is considered to be "the degree of consistency or dependability with which questions measure the attributes they are designed to measure" (Woods & Catanzaro, 1988). Its primary concern is the extent to which "random variation may have influenced the stability and consistency of results" (Field & Morse, 1985, p.139). Lecompte and Goetz (1982) differentiate factors in external and internal reliability. External reliability exists where "independent researchers would discover the same phenomena [and] requires that the methods of data collection be reported precisely and thoroughly" (Woods & Catanzaro, 1988, p.318). Internal reliability, on the other hand, "refers to the degree to which other researchers code data in the same way as the original investigator" (Woods & Catanzaro, 1988, p.319). External reliability may be enhanced by recognizing and attempting to control several problem areas; researcher status position, informant choices, social situations and conditions, analytic constructs and premise, and methods of data collection and

analysis. In order to consider researcher status position, the investigator's role and status within the group must be identified. The investigator identified herself as a nurse-investigator to each respondent and had two contacts with each individual (telephone contact and actual interview). The time spent with participants was limited varying from a minimum of one and one half hours to a maximum of three and a half hours.

The problem of informant choice considers those participants chosen to provide the data. The seventeen respondents in the study had a ratio of 14 females to three males, which loosely corresponds to ratio of female to male in those with R.A. in the general population. The ages of respondents ranged from 27 to 71 years with each decade being represented. Data was not provided by the Self Help Group Board as to the sex ratio and age range of all its members.

Social situations and conditions may also pose a threat to external reliability. Informants may not feel comfortable revealing specific information in certain contexts (Field & Morse, 1985). "Delineation of the physical, social, and interpersonal contexts within which data are gathered enhance the replicability (LeCompte & Goetz, 1982, p.39). All interviews were conducted on an individual basis, in the participant's homes thereby promoting a sense of comfort and familiarity. Time has also been noted to be an important condition to consider in data gathering. The time of day of

the contact was selected on the basis of convenience and preference for the participant. Although contact was limited to one direct encounter, the time was sufficient to establish rapport and to gather data.

Analytical constructs and any underlying premises must also be considered. While invented constructs emerge from the data as it is revealed, "their assumptions, definitions and limitations should be delineated explicitly, and their relationships to existing concepts should be clarified" (LeCompte & Goetz, 1982, p.39). The purpose of the study and the research questions, which were derived from the review of the literature and a consideration of the basic concepts of Orem's Self Care Model informed and shaped the research. The creation of categories was driven by both the emerging data and the concepts inherent in the research questions. Pertinent, limiting terms such as conventional treatment modalities and alternate treatment modalities had been previously defined. Creation of categories is a necessary and a vital step in analysis for it organizes the revealed "stream of behaviour into manageable units" (LeCompte & Goetz, 1982, p.39).

Threats to external reliability may also be evident when methods of data collection and analysis are not clearly presented. The strategies used to collect and analyze data need to be stated (LeCompte & Goetz, 1982). Analytic processes may be "vague, intuitive and personalistic" (LeCompte & Goetz,

1982, p.40). It is important that the investigator's perspective and data be shared in order for the study to achieve that which Lincoln and Guba (1985) refer to as "auditability" which is achieved when another researcher can follow the "decision trail" used by the original investigator (Sandelowski, 1986). Analytic categories used were derived from an application of the concepts inherent in the discussion of the conceptual framework and questions used to guide the research.

The consideration of internal reliability in qualitative studies is of equal importance. This refers to the "degree to which other researchers, given a set of previously generated constructs, would match them with data in the same way as the original researcher" (LeCompte & Goetz, 1982, p.32). It is also viewed as a "necessary precondition for validity" (Sandelowski, 1986, p.32). Methods appropriate to achieving reliability in quantitative studies are not readily applicable to qualitative ones due to the uniqueness and dynamic nature of human situations (Sandelowski, 1986). However, specific strategies may be used to reduce threats to internal reliability. These strategies include the use of peer examination, low inference descriptors and participant reviews of findings (Field & Morse, 1985).

The use of peer examination involves presenting transcripts and field notes, if necessary, to a colleague to determine whether the same categories and structures can be

identified within the data. Validation of categories would ideally result, but also "trends in the data not discovered by the primary researcher, may open new avenues for exploration" (Field & Morse, 1985, p.121). Two coded transcripts were randomly selected by a clinician with Masters degree in Nursing (M.N.). The research questions as well as codes derived to that point were also presented. The colleague coded segments of the transcripts without reference to the researcher's code list. Coded segments were then compared. The data was found to have been appropriately placed in the developing categories. The use of peer examination also may help to offset spurious conclusions drawn by the investigator through idiosyncratic use of constructs.

Different coded transcripts along with derived code categories were offered to another nursing colleague with an M.N. and expertise in the community clinical setting. This was felt to be appropriate because much of self care management takes place in the community setting.

Low-inference descriptors may also be used to reduce threats to internal reliability. This refers to "verbatim accounts of information provided by informants to the researcher" (Field & Morse, 1985, p.120). A tape recorder as well as taking of notes during the interview was used in order to enhance the accuracy of transcribed interviews. A variety of these low-inference descriptors (excerpts from the transcripts) are presented in the analysis of the data.

Provision of rich excerpts are considered to add to credibility.

Finally, participant review of findings may be used to reduce internal reliability threats. This will aid in determining whether the investigator and participant view the data consistently (Field & Morse, 1985). This was not done due to time constraints involved in contacting potential subjects, in conducting the interviews and in transcribing of the majority of the interviews. This was anticipated and efforts were made to summarize data, as revealed by the respondent, to the respondent during the course of the interview. If a code category seemed to be naturally emerging at the time of the interview, this was stated to the respondent who had the opportunity to accept or reject it. The limitation to this was that spurious conclusions may have been drawn. Sharing the analysis with participants has limitations, that it may distort further information by the informant's "attempt to supply answers that the informant believes the researcher wants to hear" (Field & Morse, 1985, p.121).

Implementation of Methodology

After having received ethical approval for the study, the investigator had two clinical nurse specialists with M.N.'s critique the interview guide.

Instrumentation

The instrument used consisted of an interview guide with questions, which sought socio-demographic data, followed by

open ended questions seeking data on perceptions and practices regarding R.A. and its management (Appendix H). It was designed by the investigator and was guided by the problem under consideration, the review of the literature and the conceptual framework. The questions sought data of a qualitative nature. Instrument construction was based on ethnographic and phenomenological considerations. Inherent in these is the concept of learning from people, from what they are displaying in behaviour (which include verbal interaction) and from what they share regarding their own personal lived experience (Spradley, 1979). Basing questions on these considerations has merit because they are based on a desire to "discover patterns of meaning in what an informant says" (Spradley, p.5). The primary focus of the intended interviews was the ascertaining of data about the subjective perspective of the individual regarding his/her experience.

The amount of structure sought for the interview tended toward the less structured which consisted of specific questions but asked them in a "largely open-ended format. That is, questions, but not response categories [were] predetermined" (Chadwick, Bahr & Albrecht, 1984, p.104). The interview guide consisted of rather specific topics that were covered in the exploratory situation. As Chadwick, Barh and Albrecht have noted "the exact manner in which the questions [were] asked and their sequence [were] determined in the course of the interview itself. The guide [was] used to make

sure that all of the issues of concern received attention during the course of the encounter" (p.104). A pilot test was conducted in order to determine the approximate time it would take to gather the demographic and other data as well to note the validity of tool in the degree of ease and appropriateness of responses offered by the pilot respondents.

Data Gathering Procedure

Telephone contact with each potential participant determined willingness to participate, date, time and location convenient to the participant for the purpose of data gathering. The consent was signed upon arrival at the interview.

All respondents were encouraged to seek clarification whenever a question or point made by the investigator was not clear.

For each interview the investigator sought to ensure a comfortable, quiet and relaxing environment. Each interview was commenced with essentially the same question which asked the respondent to explain or describe what R.A. was, as if explaining it to someone who did not know anything about the disease (Appendix H). Thereafter questions sought to elicit the respondents' viewpoints or concerns regarding R.A. and its management. The primary intent was to get data pertaining to attitude, perceptions, behaviours, feelings, opinions, motivation and past and present experiences within the context of the experience with R.A. Data was gathered in a

conventional manner with the interview guide used mainly as a reference in order to ensure that all chosen topic areas were addressed. At the completion of each interview and having left the site, the investigator jotted notes as to impressions of the interview, basic factors revealed, and general observations regarding the site of the interview. Tapes were then transcribed in total with the exception of areas which were divergent and did not pertain to the research topic or areas which could not be heard clearly.

Data Analysis

The data analyzed consisted of accounts, varying in detail, of the respondents' perceptions and practices regarding conventional and alternate treatments used in the management of R.A. The analysis in this qualitative methodology was "directed to document themes, patterns, and attributes of people within particular natural or recurrent life contexts or environments" (Leininger, 1985, p.5).

Analysis consisted in part of the identification of the frequency with which pertinent category responses appeared, as with demographic data and data pertaining to specific identified treatment modalities. The majority of the analysis consisted of content analysis based in part on a modified application of Giorgi's phenomenological method (Giorgi, Fischer, & Murray, 1975). By this method the description of the phenomena obtained by taped interview, was transcribed and then read in its entirety to get a sense of the whole.

Rereading determined whether the same impressions emerged a second time. Rereading also began to yield a sense of separate categories or themes contained within the description. As categories began to emerge, codes were applied to differentiate areas. Code words were derived primarily from the purpose and the research questions used in the research as well as any specific terms that each subject might have used. Rereading was done to relate identified units or categories to each other and to eliminate any possible redundancies. Analysis was aided by the use of a computer program, Ethnograph (Seidel, Kloseth & Seymour, 1983) which aided in storage and retrieval of coded segments. Saturation was sought of categories. This involves "the point at which the investigator finds no new data to add meaning to the general category" (Woods & Catanzaro, 1988, p.565). As well as seeking for repetition or commonality in categories there was a constant search for negative instances of categories or that which Field and Morse (1985) refer to as "disconfirming evidence for tentative constructs. The analysis determined any patterns and themes within the data and presented an array of the most plausible explanations of [contributing factors] of phenomena ..." (Field & Morse, 1985, p.121). Findings of data analysis are reported in the subsequent chapter.

Chapter V

FINDINGS: SELF CARE AND RHEUMATOID ARTHRITIS

Introduction

The self care practices of any individual must be considered within the context of the greater socio-cultural group of which that individual is a member. It is society which defines health and mandates the existence of and conditions for those who provide self care, under what conditions and with what specific requirements (Orem, 1985). It is the Western culture's societal expectation that adults be "self-reliant and responsible for themselves and for the well-being of their dependents" (Orem, 1985, p.54). Those who are incapable are expected to be helped to "attain or regain responsibility" for self care. As Orem (1985) notes, "both self-help and help to others are valued by society as desirable activities" (p.54).

Self care as a practice is learned according to the beliefs, habits and practices that characterize the cultural way of life of the groups to which the individual belongs" (Orem, 1985, p.108). Several respondents expressed myths or misconceptions which they had held about R.A. and which tended to reflect the beliefs concerning the disease held by greater Western society. One respondent had considered the arthritis to be a "punishment" while several others had believed that R.A. was an "old folks' disease". A few respondents had noted that they and others they knew had believed that seeing a

doctor and getting treatment, particularly early enough in the disease onset, would be enough to cure or control the disease.

The role of sociodemographic data was recognized and a research question was utilized to address this. Specifically it asked "what role do demographic characteristics (ie. age, gender, education level, employment and marital status, religion, ethnicity and length of time with disease) play in the formation of perceptions about alternate modalities"? Pertinent sociodemographic data were obtained during the initial period of the interview with the respondent.

Sociodemographic Findings

The sample consisted of seventeen respondents (n=17). Both genders were represented with one quarter being male (n=4) and the remainder female (n=13). Ages ranged from 27 years (n=1) to 71 years (n=2) with a the majority between the ages of 50 to 71 years (n=10). The mean age was 52 years.

The education level was found to be fairly high with the majority (n=10) graduates of secondary schools, while one had grade VIII and four had university degrees.

All but one respondent (n=16) reported an affiliation with a recognized Christian religion. The majority reported a moderate or strong faith (n=12).

The majority were of Anglo-Canadian origin (n=10). Although French Canadian, German, Italian, Ukrainian and Polish backgrounds were indicated, a clear sense of strong ethnic affiliation did not emerge. Only two respondents

reported the ability to speak another language. Neither respondent reported the use of the language on a regular basis.

The majority of respondents were married (n=11), three were widowed (n=3), while one was divorced and another two were single. Family size ranged from spouse only (n=2) to spouse and two or fewer children (n=3) or spouse and three or more children (n=6). Widowed individuals reported having children or stepchildren.

Data pertinent to employment status and the impact of R.A. showed the majority as retired (n=10), with six (n=6) noting this was due to the effect of the R.A. Three respondents (n=3) noted retirement was not due to ill health. Unemployment was noted by three (n=3) and was attributed to the R.A. effect. The remainder reported self employment, student or housewife status. The length of time with the disease varied from a minimum of 5 years (n=2) to a maximum of 31 years (n=1). The mean length of time with R.A. was 14.7 years. (Appendix I)

Self Care Assessment

Society expects that each individual recognizes and deals with self care requirements which reflect certain demands throughout the course of the lifespan. The goal of self care activity is therapeutic in supporting life processes and the promotion of normal function (Orem, 1985). In order to achieve this goal, the individual as self-care agent must

assess universal, developmental and health deviation requisites (Orem, 1985). It is society's expectation that the first two "become known by all educable adults" (Orem, 1985, p.86) while the last one becomes known when illness or injury arises. This final requisite produced the greatest focus for self care assessment in the experiences reported by the respondents. A question sought the data indirectly by asking what experiences with the disease prompted consideration and use of alternate modalities. Data emerged throughout the respondents' accounts as they shared their experiences with R.A. and its treatment. Analysis of data revealed that the onset and experience with the R.A. produced a definite effect on all three requisite areas for the respondents. Because of the interrelated nature of each of the three requisite areas and the desire to maintain a holistic approach, the impact of the R.A. upon all three requisite areas, will be combined for reporting of findings.

Impact of the R.A.

A major theme which emerged as a result of the consideration of this data was the impact of the arthritis. Patterns were revealed related to physical, psychological, social, daily activities or functions, and occupational aspects of life. Physical and psychological patterns were identified most frequently by the respondents. Within the physical realm, pain was the category or factor identified by all of the respondents at least once. Swelling, fatigue and

the diffuse nature of the involvement were other characteristics in the physical realm. Deformities and joint destruction were noted by several. Three noted sleep deprivation which was due to nocturnal pain. Secondary affects such as nodules, skin ulcerations and lung involvement were also noted.

Remission and flare ups, also known as exacerbations, were a frequently identified characteristic within the physical and psychological patterns. As one noted, the "unpredictability, [of the flares and remissions], it used to drive me crazy". The inability to be able to predict from day to day how one would feel and what one would be able to do led to frustration in many of the respondents. For others, the chronic pain combined with the uncertainty led to "anger" and "despair". The most intense form of despair, suicidal thoughts, was identified by two of the respondents. For another, the experience with the arthritis and the feelings associated with it were like a "lowness" with "the big, black thing ... sort of engulfing me" and "... I was feeling that arthritis was stealing me". For others, it involved an alteration in body image, with one perceiving "here I am at this age getting this crippled up". Others identified fear of dependence or a loss of control as an impact of the arthritis in their lives. One noted, "if it is acting up, you just don't seem to have any control over it". Another felt that it would "probably be easy for anyone to do, just to give up and lie

there and let it take over". Other perceptions shared by respondents revealed feelings of isolation, self consciousness, shame, and self pity.

The desire to be able to function as normally as possible was also reflected in the daily activities and functional patterns. Several female respondents noted difficulty in being able to do routine household chores such as cleaning, shopping, laundry or cooking. For some this meant feeling "useless" or having a fear of being perceived as "lazy." As one noted:

R: "... I'm sure sometimes my kids feel, well, what do you do all day mother? Things are not done when they get home. I can't get the vacuum out or I can do the dishes, but I have to do it in stages because I can't stand too long ...".

Decreased mobility related to functional limitations was identified by a majority of the respondents with some having used or currently using wheelchairs. The use of assistive devices such as support splints, shoe lifts, raised toilet seats to facilitate daily activity accomplishments were reported by many of the respondents.

Chronic pain and immobility not only affected routine daily activities of the individuals, but also had implications for social and recreational activities. Several identified an effect on the ability to carry out parenting responsibilities when the families of involved individuals had younger children, with one noting, "... I couldn't put her socks on, and I couldn't tie up her laces. She became independent very

quickly". For others it meant decreased social interaction with friends because of the unpredictable nature of the arthritis disrupting plans. For another it meant fewer movies because of an inability to sit for that period or to be able to sit in the lower, soft seat. Several others cited a loss of friends because of the impact of the arthritis. One reported, "... in the beginning I had flowers and everybody was so interested. Then it would be six months before I would hear from them".

Changes were also noted by several respondents in the area of the occupational with early retirement or quitting being cited as outcomes of the impact of the arthritis. One respondent noted with pride that productivity had not dropped during the years of employment, while struggling with the arthritis. For another, the job function was not identified as affected, but rather took its toll resulting in extra fatigue, "Since I've gotten the arthritis I've only worked part time ... I was just more fatigued. I'd come home and barely make supper. I would have to go for a nap and then get up and make supper ...". Another respondent, because of severe and degenerative arthritis almost since onset, had had little opportunity for regular employment, "... When I have worked for the summer months you partially do feel better, but then it causes everything to flare up". Thus, for the respondent, not only the requisite for health, but also the developmental requisite was not realized.

The impact of the arthritis may be made more so by the perception of absence of illness before the chronic disease onset. Several (n=7) reported such perception which was in part, related to health status and practices of the family of origin. As one noted, "I came from a super healthy family" who "didn't have a lot of stuff in our house to cure anything". Abrupt reversal of health status produced shock with one noting:

"... I don't ever remember being ... You know, I was never ever really sick. I mean I had my tonsils out, my appendix out, that sort of stuff. I was never really sick in bed or anything like that ... I was a normal, healthy adult until I was hit with arthritis. Yes, until that point, very active too which was a hard blow".

The findings have demonstrated an overview of the impact of rheumatoid arthritis on the respondents in a variety of ways. The physical and psychological effects were revealed to be most troublesome for the individuals with impact in the areas of social roles and responsibilities, social interaction, recreation, activities of daily living and occupation also being noted.

Self Care Agent

As well as data on the respondents' perceptions of health needs (deviation requisites) associated with the R.A., their perceptions of themselves as care agents were also considered. The individual determines whether a specific need (e.g. for exercise, pain control, rest or relaxation) exists and whether the individual's self care agency is enough to meet the demand or not. The individual initiates actions which reflect the

seeking of knowledge and resources, and controlling of external factors all of which require action in the interpersonal area. Individual factors such as health status, past experiences, stages of development and age can affect an individual's decision concerning the selection of self-care agent. Assistance for self-care may take the form of complete or partial provision of care, or of aid of a supportive or educative nature. The individual determines whether a deficit exists in self care and which agent, self or external health system or a combination will be used. Several respondents noted there is an element of responsibility for self. As one respondent noted the decision made is ultimately the responsibility of the individual, "... A decision is never made for you. You make the decision". In addition to the decision to seek "appropriate medical assistance", the individual as care agent needs to consider knowing about the disease and its treatment as well as learning to accept and adapt to the condition (Orem, 1985).

The following sections will consider the respondents' perception of their experiences as self care agents and their experiences with conventional, alternate and adjunct health systems as related to agency for effective self care. The key themes of knowledge, efficacy and use which emerged in data analysis will be used to provide further structure.

SELF CARE AND CONVENTIONAL HEALTH CARE SYSTEM

Introduction

The study had three (3) purposes related to conventionally prescribed treatments for R.A. (CTM's). These were to explore 1) the perceptions of the arthritic individuals regarding the prescribed conventional treatment regimen; 2) the perceptions of arthritic individuals regarding the efficacy of conventional prescribed treatment, and; 3) the perceptions that arthritic individuals have in regard to the use of or adherence to conventional, prescribed treatment modalities. Research questions sought data concerning the knowledge that individuals (respondents) had regarding R.A. and its treatment with CTM's; the source of the information on CTM's, the level or degree of satisfaction expressed with CTM's by the respondents; and what prescribed modalities do the individuals use to manage the R.A.

Content analysis of the data indicated that the respondents had a high level of experience with and exposure to CTM's of a variety of types. Data on the level of knowledge of R.A. was not the main focus of the study, but some data in this area did emerge. More importantly, data on types of CTM's and source of knowledge did emerge. The initial lack of knowledge concerning R.A. and its management noted by respondents was indicative of a self care demand which could not be met by the existent abilities at the disease onset. Respondents reported turning to health

professionals associated with the conventional health system for assistance. The reported perceptions of the respondents concerning knowledge, efficacy and use of CTM's and health providers in relation to themselves as the self care agent and the conventional health system will be addressed.

Knowledge

Knowledge was revealed to be an important theme within the data. Limitation in knowing resulting in a perceived inability to self diagnosis was a main deficit identified by respondents. This was reflected as not knowing what was going on in the body when symptoms first began to develop or how to deal with it. Few respondents suspected the cause although a majority (n=9) had indicated at least one other family member (nuclear or extended) had R.A. This not knowing reflects the pattern, type of knowledge, within the theme of knowledge. Other patterns revealed within this theme include source, adequacy and importance of knowledge.

Knowledge Types

Types of knowledge were revealed as categories of nonfactual or factual information concerning R.A. and its treatment. Nonfactual knowledge included categories of myths and misconceptions. Several respondents had noted an earlier belief that R.A. was a disease limited to "old folks". Another noted the earlier "misbelief" that if you "walk and lead a normal life it will go away".

In terms of the factual, respondents indicated varying

levels of knowledge of the disease process, its etiology and its treatment by conventional means. This knowledge was acquired gradually during the course of the condition. One respondent expressed interest in current research in the immune system while several spoke of the pathological process in R.A. Most respondents demonstrated some knowledge of the disease. All respondents demonstrated factual knowledge of the conventional treatments (CTM's) used most commonly. This factual knowledge was acquired primarily through personal experience with and use of the conventional system, its practitioners and modalities. Data revealed knowledge of several categories with which respondents had had experiences. These included health professionals, chemotherapeutic agents, physical therapy, surgery, assistive devices and inpatient/outpatient status.

All respondents reported contact with medial health professionals, 16 respondents initially with general practitioners (GP's), and one with an internist. Eventually, all respondents had had a referral to a rheumatologist. Surgeons were also noted. Most respondents indicated some contact with nurses, but none indicated a nurse as primary contact. One respondent sought advice from a friend, a nurse, about a doctor appropriate for dealing with arthritis. Contact with physiotherapists, occupational therapists, dietitians, social workers and pharmacists was also noted.

Chemotherapeutic agents were the most common CTM

identified by all respondents. All but one respondent were taking at least one prescribed medication. All respondents reported taking a variety of medications in the past. The following table provides an overview of medications taken by respondents (current or past). Nonsteroidal (NSAID's), steroidal and other drugs are represented.

| CHEMOTHERAPEUTICS REPORTED AS USED | | | | | | | |
|------------------------------------|-----------------------------------|---------------|---------|--------------------|--------|------------------|--------|
| NSAIDS | ASA | Indocid | Feldene | Naprosyn | Orudis | Butaz- olodin | Motrin |
| n = | 17 | 10 | 7 | 5 | 4 | 2 | 2 |
| Steroids | (Cortisone/Synthetic Derivatives) | | | | | | |
| n = | 10 | | | | | | |
| Other | Gold | Anti malarial | Sulpha | Immune Suppressors | | | |
| | 6 | 2 | 2 | 1 | | | |

Table I

It would appear that chemotherapeutic agents are a mainstay of conventional treatment and have served as a knowledge source about R.A. treatment.

Respondents expressed knowledge of various physical therapies used for R.A. treatment and management. As with chemotherapeutics personal experiences contributed to the knowledge. All respondents identified some form of therapy as having been used at least once. The following table provides a summary of therapies cited by respondents as being used currently or in the past.

| Physical Therapies Reported as Used: | | | |
|--------------------------------------|--------------------------|-----------|-------------------------|
| Active Exercise 15 | Passive Exercise 1 | Pool 9 | Heat/Cold/ Wax 13 |

Table II

Many reported having used a combination of prescribed physical therapies during the course of the R.A. As one noted, "I had physical therapy, yes exercise. First I took it on mats in a gym, and then he put me in pool therapy. I did exercise for six weeks in the pool".

Assistive devices were reported as used by a majority of respondents (n=12). These included the use of shoe inserts, neck braces, hand or leg splints, support hose, crutches, wheelchairs, raised seats, and special utensils to help with daily self care activities such as hygiene and food preparation. Rationale for use of the devices ranged from prevention of further joint damage to symptom alleviation (pain reduction).

A majority of respondents (n=13) reported the use of surgery to deal with damaged joints, with knees, hips, fingers and shoulders being cited most often. One reported skin grafting to promote healing of a leg ulcer which was the result of R.A. Several reported surgery to more than one affected joint.

A clear majority of respondents (n=14) had been hospitalized while three received treatment solely on an

outpatient basis. Reasons for admission ranged from need for surgery, other forms of treatment or confirmation of tentative diagnosis.

The use of a variety of conventional prescribed treatments contributed to the gaining of knowledge by respondents. Their experience with various CTM's also developed a greater factual knowledge base.

Knowledge Source

Knowledge sources were revealed as being professional and nonprofessional. All respondents (n=17), directly or indirectly identified health professionals as a primary source of information or knowledge about R.A. and its treatment, with physicians, PT, OT, nurses cited in descending order as sources.

Physicians from residents to specialists were reported most frequently as a source of knowledge, with physio or occupational therapists being cited next most frequently. Use of both health professional groups was related by some respondents,

R: "Until I went to see the specialist and he sent me to see the occupational therapist to try and find something to put in my shoes to help me walk better. They tried to explain why the foot needed some support in this way".

Knowledge Importance

Knowledge about R.A. and its management was viewed as being important to have to dispel myths and misconcepts about R.A. Some respondents expressed fear or anxiety when they did not know what was happening. As one noted:

R: "... I am one of those people who has to know everything that is happening to me. So when I was going in for my first operation I did not know anything ... The nurse told me everything right from the very start to the end. That helped me. I guess some people just don't want to know, but I had to know approximately what was happening ...".

Several respondents cited the need for information in order to make decisions effectively concerning planned treatment. One revealed, "I don't make rash decisions on the spot ... I need the background knowledge before I make a decision". For another respondent, knowing more was equated with coping better related to reduced uncertainty and a reduced sense of being the only one effected.

Knowledge Adequacy

Having adequate knowledge about R.A. and its management was valued as a necessary component of self care. The pattern of adequacy was reflected in the categories of the knowledge about R.A. and its management held by the respondents or by others. Included is the perception of the adequacy of knowledge held by health professionals providing care.

The initial inadequacy (deficit) of knowledge held by respondents was reflected in their misconcepts and in turning to the conventional health systems when symptoms appeared. Enhanced knowledge base was reported as achieved through personal experience with R.A., contact with health professionals and use of various CTM's.

Respondents comments also indicated that there was an expectation for health professionals to know. As one noted:

R: "You have to have that from the care professionals. They can't tell you the worst and just leave you hanging there. I don't think they have to go into detail. They just have to be able to answer your questions".

One respondent indicated that there was not the expectation for all health professionals to have knowledge of all aspects of arthritis. In commenting on whether the care providers (nurses) did any teaching, the respondent noted:

"No, they did not do any teaching at all. First of all they had only had one other shoulder, so their knowledge base was limited. They did give me some support but they did not even know how to get the sling on".

There was an expectation, for health professionals to have an adequate knowledge base in order to be able to provide the required information to the individual. Several respondents reported satisfactory level of information sharing by professionals such as physicians, O.T.'s, physiotherapists and a dietitian.

A majority of respondents (n=13) indicated at least one instance of knowledge dissemination deficit (inadequacy) by health professionals with physicians in particular noted by a majority (n=9). One respondent, noted a lack of sufficient explanation and reported:

"... There were so many pieces of information that seem to be implied; that you know all about it if you have any sort of level of being articulate at all. They think you know a lot more than you do. So, nobody ever really explains to you what it is ...".

For several others, perceived inadequate dissemination by professionals was rooted in there being "no coordinated team approach" by which individuals would be directed to resources,

such as "film strips and where they are".

The use of "jargon" was also noted by several respondents. One sought more information, but did not feel satisfied with the interaction and noted, "I have asked them but they talk in medical terms. They don't talk ordinary".

Knowledge was revealed to be a major factor in the individual's consideration of self care. Respondents comments indicated that all categories of health professionals were involved in the adequate or inadequate dissemination of information which contributed to a sense of satisfaction or dissatisfaction and contributed to the ability to perform self care.

Efficacy

Data revealed that a definite variety of conventional treatment modalities had been used with equally varying perceptions of efficacy reported. Perceived efficacy was a key theme that emerged. Efficacy associated with the conventional health system, its practitioners and modalities resulting in varying levels of satisfaction was reported by the respondents. Perceived efficacy was related to patterns of tangible and intangible factors which contributed to the reported satisfaction or dissatisfaction. The pattern of tangibles included categories reflective of specific therapeutic modes such as medications, physiotherapy, devices, surgery, hospitalization, of practitioners and of resources. The intangibles pattern included factors or categories

reflective of the interpersonal and communication realm, support, interpersonal relationships and participation in decision making.

Efficacy and Tangible Factors

A contrast of perceived benefit versus risk was revealed related to the perceived efficacy of the conventional health care system. Perceptions ranged from benefit (positive effect), limited benefit, neutral (no benefit or risk) to risk (negative effect). Satisfaction or dissatisfaction with the conventional system was in part related to perceived benefit. Analysis revealed that all respondents had experienced some degree of benefit with prescribed treatment and expressed varying degrees of satisfaction.

Chemotherapeutics

Medications (chemotherapeutic agents) were cited most often in relation to perceived benefit. Several expressed a perception of strong benefit with a drug seen as the key factor:

R: "Well, its the Indocid. I take one at night. I took this one pill at night and I woke up in the morning and I felt like I came back to the world of the living ... but the difference ... remarkable and after that my attitude changed ... I rely on that Indocid, I credit that with everything".

All respondents identified limited benefit with at least one chemotherapeutic agent. As one noted:

R: "I was also taking the entrophen at the time. Although the entrophen had quit working ... When he first put me on the entrophen it was wonderful. It didn't feel like I had arthritis, but then gradually it wasn't doing its job because the arthritis was getting worse".

A neutral (neither positive nor negative) affect was reported by several of the respondents regarding medications used. This perceived neutrality involved single or various medications tried.

All respondents identified negative affects as related to specific medications, either from actual experience (n=15) or potential experience (n=2) based on information from others, ranging from mild symptoms to more severe incapacitation. The two who shared vicarious perceptions of negative side effects related these perceptions to very specific drugs. One of these respondents noted:

R: "Well, I guess I have never had steroids and they have such terrible side effects and anybody who is on them is trying to get off. But somebody who has never tried them is fairly curious about how miraculous they are. Do they totally eliminate the pain? However, I don't think I would ever really ask to be on them ... I don't really yearn for steroids, because I know they are so dangerous ...".

Respondents' comments indicated that, all had experienced some degree of benefit or negative effect from the various chemotherapeutic agents used in the course of the prescribed therapy.

Physical Therapy

Physical therapy was also reported as producing a similar range of effects. Respondents reported use of and perceived effectiveness regarding exercises, pool therapy, heat and/or cold therapy and wax therapy. One respondent who reported physio as beneficial and validated the perceived benefit of exercises, noted

"... I'll know definitely whether its my exercises that helped me and I think that it does. I've seen it before. I've done it before. I quit and done it and as soon as I start doing my exercises again, it [pain] goes away ...".

For many of the respondents there was a clear benefit derived from pool therapy. One respondent noted that approximately 22 individuals had been involved with a particular "Y pool programme" and had "enjoyed it and benefited from it".

Several respondents indicated that while some discomfort may have been associated with doing various prescribed exercises, nevertheless benefit was derived mostly.

For another respondent, exercises were considered to be vital therapy which was an important component in remaining functional. The respondent noted, "If I didn't do the exercises, I'm sure I wouldn't be able to move".

Respondents' comments concerning the use of heat/cold therapy or wax therapy reflected the range of perceived efficacy with more perceptions of neutrality or risk reported. Several respondents reported that some degree of benefit had been achieved. One noted that "ice was much more soothing" (than heat). For another respondent hot wax had been tried on the hands with neutral effect reported. Another found wax soothing but would not use it at home "because it is too big a danger".

The respondents' comments indicated a perception of the efficacy of various physical therapies. These perceptions

reflected definite benefit, limited or no benefit and negative affect or risk which was actually or potentially derived.

Hospitalization

The majority of respondents had been hospitalized for the diagnosis and or treatment of R.A. The perceptions regarding the hospitalization experience ranged from beneficial to negative. Perceived efficacy tended to be reported as related to specific outcomes or expectations such as pain relief or straightening of limbs. When the expected result did not happen, there was a perception of neutrality of the conventional prescribed modality, that is hospitalization.

One respondent recalled that past hospitalization experiences tended to be negative, although the initial admission had resulted in a perceived benefit which took the form of a diagnosis of the condition. Subsequent perceptions of ineffectiveness were related to negative experiences with treatment and with no improvement in condition.

Assistive Devices

The majority of respondents (n=12) had used assistive devices and noted some degree of benefit and hence a sense of satisfaction from the perceived efficacy of the device used. One respondent reported using inserts in shoes in order to facilitate normal daily function, such as walking. The respondent commented on the perceived benefit:

R: "Yes, the shoe inserts seemed to allow me to walk a lot easier in that I didn't have the feeling I was walking on hot coals or on nuts all the time and this seemed to provide some relief to my knees. After I had the insert,

my knees seemed to recover. In that sense, I think that the inserts certainly were a valuable part of the treatment and they are so comfortable that I still wear them today, although I don't have to".

Several other respondents reported deriving no benefit and had perceived a negative effect when an assistive device or devices were introduced as treatment.

A few respondents reported that an assistive device had provided some degree of relief, thereby experientially validating, the meaning of the result sought. Despite this, the perceived efficacy was not sufficient to produce the result or outcome sought such as straight, functional hands. A few respondents reported using an assistive device as an adjunct prior to another more efficacious prescribed treatment. One respondent reported using a device as an occasional adjunct:

R: "... Yes, I guess I did have some of their devices for a while, the toilet seat, wrist support, splints which are for use at night. Yes, I use them periodically. Some times a wrist will start to go. Before I had my surgery, with both wrists I would wake up during the night and my hands would be all twisted so I started to use the splint and it straightened it right out. Once I had the surgery, it has never bothered me since ...".

Surgery

Surgery was cited frequently by the respondents as having been tried in order to achieve some benefit. A majority (n=13) had had at least one surgical experience and reported perceptions of efficacy which ranged from strong benefit to little or no benefit. No respondents indicated a negative or adverse outcome to the surgery, although one noted a

perception of increased pain as a potential outcome and therefore had refused to have any.

The respondents who reported a benefit were in no doubt that the surgery had been the main factor in producing the beneficial effect. As one noted:

R: "... I have had hand and knee and hip surgeries. ... Then in [year] I had a knee replacement. Oh ... they all feel better. I can do a lot more with my hands. I have no more pain in them. I guess I can do more because the pain is gone, but I also have more flexibility in them now. Oh, I am feeling really good now ...".

Several respondents indicated a limited benefit, either of degree or duration of effect with the surgical treatment tried.

One respondent noted that the perceived lack of benefit resulted in a sense of dissatisfaction due to a failure to achieve the desired outcome. This perceived lack of effectiveness resulted in disappointment because the respondent noted there was "... great hope and faith in these things that were really going to help. Well, they didn't help".

Practitioners

Practitioners within the conventional health system were also noted by respondents in considering efficacy. Consideration of the credentials of conventional practitioners produced perceptions of efficacy reflective of varying satisfaction. The perceptions concerning credentials tended to be revealed more implicitly. Consideration of credentials involved not only the qualifications, reflective of

educational preparation at an institution recognized and accepted by society, but also expectations for health professional behaviour related to knowledge base and dissemination of knowledge.

Some of the respondents indicated satisfaction or a perception of more efficacy when considering conventional practitioners with specific credentials. A few expressed a perception of efficacy related to a differentiation in credentials. One respondent was explicit in expressing a perception of the part credentials play and noted,

R: "... I always thought that arthritis was hereditary, and because there was nobody in my family with arthritis, so I asked the doctor ... the only trouble was that I was asking the family doctor and he just said to me that it was a virus ...".

The perception of credential tended to be placed in the larger context of the conventional health system in which faith and trust were placed. As one of the respondents noted, "... they are going to give you the best. Like [rheumatologist] has got the best hot line to university research possible ...".

Comments by several other respondents suggested that practitioners in the health care system had "credentials professionally" and served as sources of information and verification concerning other modalities. As one respondent noted, the physicians "and the rest of the therapists and the nurses know". For another respondent it was a question of faith "with the current medical treatment.

Practitioners within the health system were perceived by

most respondents as being efficacious in the management of R.A. The perception of efficacy was related to a faith or belief in the health system and its practitioners and the specific credentials held by the practitioner.

Resources

Resources associated with the health system were noted by a majority of the respondents (n=12), in their consideration of the efficacy of the health system. All respondents who addressed resources noted they were either readily available or available in a limited capacity. None noted only a lack of resources.

Respondents' responses indicated that a variety of resources were available which ranged from physicians to home support services, such as Home Care. The loss of a pool therapy program was cited by many of the respondents. The particular pool program had been identified by a majority of the respondents as being beneficial in facilitating exercise, promoting flexibility and enhancing well being. It has been identified as a limited rather than lacking resource because other swimming pools were available. One respondent articulated the dissatisfaction associated with going to other available pools:

R: "... It is really unfortunate because we have these pools all over the place and there isn't one we can go into ... Part of the problem is that the water is very cold. Part is also that they have very good supervision except that it is geared to M.S. and Polio patients and they have no idea of how to treat an arthritic patient".

Respondents commented on the limited number of specific

health personnel available generally. As one noted, "... There are just not enough doctors. There are more in one town in Quebec than we have in all of Manitoba. It must be really bad out in the country ...".

Comments by respondents indicated a perception that resources were a necessary component of the self care and management of the arthritis. Various resources were noted by respondents. Ready availability of resources produced general feelings of satisfaction among the respondents. Limited availability and non availability produced dissatisfaction among the respondents.

Efficacy and Intangible Factors

Intangible factors were also noted by respondents as important elements in the perception of efficacy and the feelings of satisfaction or dissatisfaction with the conventional health system. Respondents expressed varying degrees of satisfaction reflected as categories of intangible factors. These included interpersonal contacts, knowledge, participation in decision making and support.

Interpersonal Contacts

Communication and time were found to be factors in the interpersonal category. Respondents identified communication within the conventional health care system which produced satisfaction and/or dissatisfaction based on the quality and quantity of that experience.

Several respondent expressed perceptions of comfort in

their communication with and the ready availability of their physicians. One noted,

"... At first I was seeing him at least once a month ... now I'm down to twice a year ... and there is always the process there that I can phone them at any time that I feel there is a change ... I don't feel uncomfortable at all in that. I just feel that I haven't had the necessity".

Several respondents indicated that time was a factor in the perception of satisfying communication and interaction with health professionals. One respondent indicated a positive perception of interaction with nurses and reported, "... I guess they took more time. These were older nurses and usually on the night shift ...". For another respondent, the openness of communication and sufficient time were factors in forming a positive perception. The respondent noted:

R: "... He is slow sometimes. Sometimes you have to wait, but you can ask anything you want and he talks to you and talks about what's bothering you ... He never rushes anything ... He makes sure that you've asked all you want and I have my list and I pull it out ...".

Other respondents reported lack of time in communication as creating a negative effect/dissatisfaction in them. One noted, "physicians don't take a whole lot of time to talk to patients".

For another dissatisfaction or a negative perception was related to the manner in which the diagnosis of arthritis was shared:

R: "This doctor is very blunt. He just said, 'You've got R.A.' and that is all there is to it. Yes, that was the G.P. and it was about [x] years ago. I was in pretty bad shape".

Open communication resulted in increasingly positive perceptions of health professionals and interactions with them for several respondents. As one respondent noted, "... a lot of the therapists, especially the therapists, have become very good friends ... and we feel like there is somebody we can talk to". This was attributed, in part, to the respondent becoming more "assertive and more confident", resulting in feelings of being "friends" with the physician and of being "more at ease now talking to him than I ever did ...".

Knowledge Dissemination

Knowledge, and its dissemination by health professionals was also revealed as a factor in the perception of the efficacy of and related satisfaction or dissatisfaction with the conventional health system. Respondents' comments indicated perceptions of both adequate and inadequate information dissemination by health professionals.

For one respondent, adequate dissemination occurred within the health care agency, in the "O.T. department" where the respondent viewed "a couple of slide tape presentations" and noted:

R: "...and they were absolutely the best things I had seen on arthritis published by the Arthritis Society and had I seen those when I was first diagnosed I would have felt so much more on top of the situation".

Respondents' expected health professionals to have an adequate knowledge base in order to be able to provide the kind and level of care as mandated by societal expectations. This care includes sharing of information. Respondents'

comments indicate a perception that this did not always occur and hence a sense of dissatisfaction and perception of decreased efficacy of the health system occurred. One respondent noted:

R: "... I think that my rheumatologist is wonderful but I think he always assumed that I knew more than I know. No, I didn't ask him because you don't even know the questions to ask. You don't know what you don't know ...".

This was echoed by another respondent who noted, "you have to have that from the care professionals. ... I don't think they have to go into the detail. They just have to be able to answer your questions".

Data indicated that while respondents expected health professionals to have an adequate knowledge base and to share it, this did not always happen. Effective communications and time were also seen as a necessary component in adequate information dissemination.

Decision Making

Participation in decision making was noted by a few of the respondents when considering their experience with the health system and its professionals. A few respondents indicated that decisions were essentially made by the physician in whom belief and trust had been placed. Several respondents noted having some degree of participation in the management of their arthritis with a resulting positive perception. One reported, "... I have gone in and said is this a candidate for Cortisone. He then asked me if I want it

and I say let's go. I don't hesitate". Another respondent indicated a similar experience in which some say or control was had in the management of the prescribed treatment.

One other respondent indicated a negative experience of decision making regarding treatment management. It was revealed that early in the course of the arthritis a physician had "tampered" with the medications with the respondent having no input with the result that "everything was way out of control again". The respondent's dissatisfaction with nonparticipation in decisions had been modified by the current practice of managing the dosage of medication at home in conjunction with physician input.

Participation in decision making concerning treatment was noted by some of the respondents. Positive perceptions were based on active involvement in the decision making process. Those respondents who wished to participate in decision making and were not allowed to do so felt dissatisfaction which resulted in a negative perception of the health system and its efficacy. Those who did not wish to actively participate and were not required to do so, reported feeling comfortable or satisfied with the arrangement.

Support

Support emerged as an important factor which contributed to a perception of the efficacy and satisfaction with the conventional health system. The importance of and the expectation for support was addressed by one respondent who

noted:

R: "... I think that that is a big part of nursing, to help the patients protect their dignity and treat them the best you can. That they are persons and you can't just be a biological bag ...".

Data obtained from respondents revealed varying perceptions of support received from health professionals. Several respondents clearly identified health professionals as providing support in a physical, psychological or emotional way. One respondent was adamant in expressing the positive perception formed of the psychological support offered by a physician:

R: "... I don't think he gave me a whole lot of information. I think he gave me support. He's a very caring person. He's the kind of person who hugs you and he'll say, 'you take care of her. She's in a lot of pain', and I appreciated that ... [spouse] knew that but to have a professional say she's suffering that really meant something".

Several respondents identified the Self Help Group as a source of support. For some, it helped to foster feeling "normal because there are other people who are willing to talk about". For another respondent the Group meant being able to talk to someone who could understand the impact of R.A.

In summary, a definite variety of tangible factors emerged related to the perceived efficacy of the conventional health system, its practitioners and modalities. Responses indicated varying perceptions of efficacy for them. Perceptions of strongest efficacy appeared to be related to chemotherapeutic agents and surgery. The credentials of practitioners and belief and trust in the conventional system

were cited by many respondents. Generally, there was a reported benefit with associated satisfaction for prescribed, conventional treatment.

Intangible factors were also reported as sources of satisfaction and perceived efficacy in the respondents' experiences with the conventional health system. Communication, time, participation in decision making and support were noted. A majority of the respondents noted some deficit in the dissemination of information. Knowledge of the condition and its treatment as well as a perception of the efficacy, and inherent satisfaction were elements in the decision to continue to use the health system and its modalities. As Orem (1985) has noted, limitations to self care occur in the form of not knowing or of not having "result achieving actions". Thus information and a perception of some degree of efficacy are vital to the selection of a system and its modalities for ongoing self care.

Factors in the Use of the Conventional System

A purpose of this study was to determine the perceptions that individuals with arthritis had concerning the use or adherence to conventional prescribed modalities. A research question sought specific data on what prescribed modalities the respondents used to manage the R.A. Use has been considered in two senses. The use of these treatments when first prescribed involved "use" in the first sense. In order to be able to assess its effectiveness (ie. benefit derived or

not) use had to occur. The second sense in which it has been considered involves the decision to use it in an ongoing manner. Only the individual could determine whether use of a specific modality had been a "result achieving action" (Orem, 1985, p.125) in terms of the outcome sought, such as pain relief or normal activity. It was not a purpose of the study to determine whether the respondents adhered strictly to prescribed treatments or not. Use was considered in the sense of employing a treatment (or using the system and its practitioners) as a relatively consistent ongoing practice. The respondents were given an assurance that the focus of the study was not to judge actions regarding use.

Analysis of the data revealed a variety of factors related to the respondents' ongoing use of conventional health system, its practitioners and modalities. These factors may be subsumed under the overall theme of treatment selection and use. The two main patterns which emerged within this theme included respondents' perceptions of benefit versus risk associated with CTM's and belief and trust in the conventional system, its practitioners and modalities. Disease condition, support, knowledge, validation, and resources are other factors which emerged.

Benefit/Risk

The benefit/risk category was found in all respondents' responses. All respondents (n=17) cited some degree of benefit from at least one CTM. Most of the benefit appeared

to have been received from chemotherapeutic agents of some kind with surgery, physiotherapy and assistive devices also being cited. The ability to move around again and be "useful" was cited by another respondent as the beneficial outcome of medications and exercises. The two forms of treatment were important as a combination for the respondent who noted:

R: "... treatment has enabled me to get on with my life again ..." and where there had been an improvement "... on a very steady basis to the point where today I don't have, as far as I'm concerned a problem with pain. I am virtually free of pain. I am extremely flexible".

The respondent also noted because of "better health", an increased amount of exercise and running were also possible. The importance of adhering to and continuing the prescribed treatment was identified in order to maintain the benefit obtained.

Other respondents expressed a lesser degree of benefit with the prescribed treatment, but noted nevertheless that continuation provided some relief. As one respondent revealed, "You have got to take your arthritis meds or you wind up in more pain the other way". Another respondent indicated little or no lasting benefit with CTM's due to the development of either negative effects or tolerance, with a decreasing therapeutic effect using the prescribed treatment. Because of the risk of negative effects the respondent was currently on no medications for the arthritis.

Another respondent had experienced a variety of negative effects related to prescribed treatment, but expressed a

greater concern regarding the risk related to possible infection with surgery. The respondent noted,

R: "... I'm reluctant to have surgery on my feet if I'm having infection. And I know people who have had their hips replaced and got infection in there and had nothing but problems. You were better off the way you were before".

The respondent demonstrated the weighing out of the risks versus the benefits by determining that when surgery was contemplated not so much to make the hands "look better" but rather "work better", the surgery was rejected on the basis that "I didn't figure that it did any good for the amount of time that they had to spend in there and the pain and everything. It wasn't worth it".

Belief and Trust

The respondents expressed some degree of belief or trust in the health care system, its practitioners and modalities. The importance of belief was articulated by a respondent who noted, "the belief has to be there that it might work". Several did express more trust or faith in specialists as opposed to general practitioners, but they also expressed clear belief in specific treatments such as exercise, physio or medication. One respondent noted, "... I think without it, in fact I was convinced if it didn't work for me and at the rate I was going I would be a wheelchair candidate for sure. Yes, I was lucky enough and they were lucky enough to find the right drug for me".

For a few respondents, belief in the health system was

somewhat more tempered. One noted:

R: "... Maybe some people are dissatisfied, but maybe I am so naive that I figure that this is the god's truth and nothing else is going to help me. So far I am satisfied. Well, sure I believe it is helping me and what else can I do. I don't have any other alternatives".

Another respondent noted less belief in the medical system with the reservation being related to the nature of the medical system:

R: "... I think that doctors and rheumatologists are a little leery to recommend the new therapies. It is all sort of medical model, and I think that they are really leery of chiropractors [etc]. ... although I think they are seeing the connection between body and mind because I know the wellness group which [person] instructs, I know they are quite optimistic about that and now the doctors, the rheumatologists themselves are referring some of their patients to that, which is mainly doing the body mind connection and education. So I think they are becoming a little more open in terms of psychological ... actually something that is a little more holistic is something that I would prefer, a more holistic approach. Not just your medical model ...".

Most respondents indicated a belief or trust in current conventional health system, regardless of a perception of no alternatives, or of models not being wholly acceptable.

Disease Condition

All but one respondent (n=16) indicated disease condition and its desperate state as factors in either seeking or continuing with conventional treatment modalities. Pain, was identified as a desperate disease condition by all respondents. One respondent described the impact of the disease in the decision to try a specific treatment, and what it had meant for quality of life,

R: "... When he first asked me to go on [drug] I was so afraid of what I thought was a stronger drug that I refused. So I played along with the rest of the physiotherapy and entrophen for so long and when it finally got to the point when I couldn't manage at all anymore ... Out of desperation finally I tried it and now I realize I probably did the wrong thing ... I've told people today that I understand their fears. I see people all the time who are as bad as I was and they're afraid to start on [drug] and I say to them, don't be afraid. That's better than this. ... But you're not doing yourself a favour staying this bad. That's what I believe today and I don't ever want to stay in that rut again. Certainly I'd be afraid of the side effects of any new drugs he gave me. But if in the end it shortens my life by ten years or whatever at least I've had something in between".

The disease condition and its impact contributed to nonadherence to exercise for one respondent whose knowledge of exercises and their importance was not enough to combat the effect of the disease. The respondent noted "... And [the physio] was so good at explaining the inner workings of my hands, and I try to do the finger exercises, but it hurts my hands and it makes them swell up too much ...".

Another respondent noted that there was no choice to having cortisone injections given into specific joints to relieve inflammation and pain, even though the injections contributed to further damage noted. The respondent noted that there was a lot of "mechanical damage" and this meant there "will be more surgery in the future because my foot is really bad ...". Thus, the disease condition and its concomitant desperation produced an ongoing use of the conventional system, its practitioners and modalities.

Support

Because of the nature of the disease and its potential and varying impact, support from others is an important factor. All but one respondent (n=16) identified support as one element in their arthritis experience. Several spoke of the lack of understanding of family and friends at times, but more so of the lack of understanding of the condition and of any genuine empathy by the general public.

Respondents noted, "... you don't really understand it, yes, until you get it". Several reported the "hard time believing" that members of the general public had when they were informed of the variety of effects such as pain, depression, loss of employment and decreased social relationships which the R.A. produces.

Many respondents spoke of the support which had been received from family, friends and employment situations. Speaking of the importance of family, one respondent noted, "...and they tried very hard and I think it was through the love and concern of my [spouse] and my family that I decided to get better". A few spoke of support services available to assist with daily activities and routine household chores.

Several identified a lack of support from professionals in the health care system. Both nurses and physicians were identified as contributing to a lack of support for not only individuals but also families of those with arthritis. The lack of support for diagnosed individuals and families was

echoed by a respondent, who perceived a need for "more active counselling" and of "something more [having] to be done for the families because one thing affects the other".

Communication and interpersonal relationships with health professionals were also indicated by the respondents. Dissatisfaction, generally with physicians was related to lack of time, inadequate explanations, use of jargon and lack of listening. Others who expressed some satisfaction with the physicians tended to be assertive, have more open communication and perceived more attention as being given to them.

Knowledge

The importance of knowledge was readily revealed by the data as a primary factor in considering and using conventional treatments which would contribute to effective self care. Knowledge provided effective self care by making decisions about which particular treatment to choose or reject. One respondent noted:

R: "... I mean I could have easily refused the [X] drug, so I think they leave it open. They place the facts in front of you and they let you make that decision. As far as the mental part of me trying to get well that way, to help my body, I think the onus was definitely on me for that ... [and] for meds I usually try and get as much information as I can. I don't make rash decisions on the spot ... He told me the facts and I went home and thought about it ... I weigh the advantages to the disadvantages and how much of a risk I am willing to take. Oh yes. Risk taking is a part of it ...".

Health care professionals were identified as the main source of information or knowledge by the respondents. It was

also noted by several of them that there had been a deficit in the dissemination or spreading of that knowledge or information.

The Self Help Group also tended to be cited frequently as a source of information as and as a reinforcer of learned information about conventional treatments. As one noted, "no, like through Self Help they had the sort of same ideas that I did, that exercise is what keeps you going. Exercise and drugs ...". It was also identified, as a learning resource to which physicians referred their patients.

Validation

Several respondents indicated that health professionals played a role in assisting them to determine the soundness of activities planned. A few respondents referred to their preference to see treatments determined through "scientific research". One spoke of the Arthritis Society, as being able to "do tests" of any potential "cures". Another, speaking of checking all things out first, noted, "... it would be better for them, before they take anything or do whatever it says to do, that they were to approach their physicians".

Validation by personal experience was also described by a few. As one respondent noted:

R: "... if you understand that the disease comes and goes and recedes on its own, you have to be extremely careful to even believe that the medication you are taking is what is giving you the relief. I would say that it is only after taking this medication for three and a half years and having forgot to take my pills on occasion that I realize the benefits of this and I'm quite certain that I can attribute it to my prescribed medicine".

Resources

Several respondents identified resources as a factor in the use and adherence to CTM. Of the twelve (n=12) who noted resources during the course of the interview, eight (n=8) referred specifically to a pool therapy program which had been discontinued. Others cited a lack of specific resources for "mental problems" associated with arthritis or other resources or support programs available for families of individuals with arthritis. Rather than citing a lack, one noted a long wait was required before the respondent was able to get to see a rheumatologist, which emphasizes the lack of rheumatologists in the community. Two (n=2) expressed some satisfaction with availability of resources with one referring to the ease with which the rheumatologist could be contacted if necessary and the other referring to the general availability of more sophisticated treatments and facilities in a larger urban centre. The loss of the pool program appeared to be the main resource lacking for a number of respondents.

Summary

In summary individuals use a variety of conventional, prescribed treatment modalities to manage their arthritis. The consideration and use of these modalities is based on a variety of factors. The primary ones which emerged were perceptions of benefit versus risk and belief or trust in the health system, its practitioners and treatment modalities. The majority held perceptions of some degree of benefit from

CTM's and this perception was largely derived from actual use. Risk was considered with several indicating an acceptance of some degree of risk for benefit derived. The majority indicated a clear belief or trust in the current health system with physicians cited most frequently as the embodiment of that directed belief and trust. For a few, continued use of CTM's was related to belief only in the system rather than actual derived benefit. For the majority, belief was in both the benefit and the system and its practitioners. For many of the respondents a desire to seek and use treatment was based on the impact of the disease condition. Knowledge was noted to be a necessary factor in assessing one's own condition, the impact of prescribed treatment and in making decision about self care activities. The importance of support from and effective interpersonal relationships with professionals and nonprofessionals alike were reported by many of the respondents. Validation of information by professionals and by knowledge gained through personal experience was cited by a number of respondents. Relief of disease symptoms due to remission rather than treatment was considered by only a few respondents, with only one respondent explicitly noting remission due to specific treatment. While availability of resources was noted. There was also the tendency to articulate a lack of resources. In conclusion the consideration and use of conventional, prescribed treatments by the respondents was related to a variety of complex

factors.

SELF CARE AND ALTERNATE HEALTH CARE SYSTEMS

Introduction

Individuals, in attempting to meet self care demands and having recognized a deficit in the ability to perform self care, might also turn to alternate systems of health care to meet identified self care needs. The study sought data pertinent to this.

The study had three purposes related to alternate treatments (ATM's) which might be used to treat R.A. These were to explore (1) the perceptions that arthritic individuals had regarding alternate treatment modalities; (2) the perceptions of arthritic individuals regarding the efficacy of alternate treatment modalities and; (3) the perceptions of arthritic individuals in relation to their use or adherence to alternate treatment modalities. Research questions sought data concerning the knowledge the individuals had regarding ATM's, the source of information regarding ATM's, the information concerning ATM's which was provided by health professionals in the conventional health system and the information about ATM's which was shared by individuals with R.A. Data was also sought concerning the value given to ATM's, the effect of any ATM's used; the ATM's used to manage the R.A.. Perceptions regarding the experience with R.A. which prompted consideration or use of ATM's was also sought. The role of self help groups in the perception and use of

ATM's end and the role of sociodemographic characteristics in the formation of perceptions about ATM's were also considered. Data will be reported on the basis of the above stated purposes and questions which were used to guide the data gathering.

Analysis of the data revealed that the respondents did not have as high a level of experience with or exposure to ATM's as had been revealed with consideration of CTM's. Any deficit in knowledge about R.A. and its management did not appear to contribute to an initial seeking of assistance from practitioners or modalities in the alternate system. No respondents reported turning to ATM's first in an effort to manage the R.A. Consideration of the data reflected various degrees of knowledge of ATM's, and perceptions of the efficacy and use of ATM's.

Knowledge of ATM's

As with the consideration of CTM's, knowledge remained as an important element or factor in self care. Knowledge of ATM's was not found to be derived largely from personal use. Data also revealed that health professionals and care providers associated with the alternate treatment system were not approached or used as readily as the conventional system in self care. Data analysis showed that all of the respondents (n=17) had some knowledge of ATM's.

Knowledge was a major theme within the data. Patterns of knowledge concerning ATM's were revealed as categories or

types of ATM's and source of knowledge.

Category determination of ATM's was based on characteristics or attributes of the modalities identified by respondents. Categories, based on the modalities were natural ingestibles, topicals, nonconventional pharmacological agents, psycho/spiritual means and others. The category "other" included miscellaneous items not readily grouped into specific categories.

Natural Ingestibles

This category formulation was based on items which may be consumed by humans and as such are made up of essentially natural as opposed to synthetically formed substances. This category accounted for the greatest number of references. Natural ingestibles were reported as cod liver oil, dietary (in the form of specific drink or foods), herbal remedies, vitamin therapy and concoctions.

The following table provides an overview of citations for specific items.

| | ALTERNATE TREATMENTS - NATURAL INGESTIBLES | | | | | | | |
|-----------------------|---|----------------|----------------------------|--------|-------|-------------|----------|-------------|
| TYPE | DIETARY | | | | | HERBAL TEAS | VITAMINS | CONCOCTIONS |
| | COD LIVER OIL | VEGET ARIAN | ITEM ELIMIN ATION | CELERY | LIVER | | | |
| RESPONDENTS CITING | 15 | 1 | BREADS 1 TOMATO 1 | 1 | 1 | 9 | 4 | 5 |

Table III

Mention of the items does not necessarily indicate knowledge of it based on actual use, although several did indicate a use. As one respondent noted;

R: "I did buy cod liver oil pills, though ... No, I haven't used them yet. I bought them about a month ago and I still haven't taken one, isn't that funny".

One respondent indicated having knowledge that "tomato" aggravates it [R.A.] while carrot juice had been suggested to the respondent as a means to help manage the condition if "you drink gallons and gallons of the stuff". [said with a laugh]. The respondent noted, rather, a belief in "a well balanced diet" as opposed to a specific diet or nutrients. This perception of a balanced diet in the management of the arthritis condition was echoed by other respondents.

Herbal remedies involved teas of various types with alfalfa, ash leaf and camomile being noted rather superficially by respondents. One respondent indicated some knowledge of the purpose of the tea as well use of it:

R: "... And she sent me this huge two pound bag of ash leaf tea from this place in Montreal and I was supposed to sip this for five minutes and it was supposed to take away all the inflammation ... but I drank that ash leaf tea faithfully for two years".

Vitamins were reported as a therapy related to arthritis management. One respondent was able to report knowledge of specific vitamins actions which was considered as a rationale for their use:

R: "So I take vitamins. I used to take more. I'm taking less at the moment. ... I was not taking it for any specific reasons, but I had heard that A

was good for inflammation so I was taking A as well as multivitamins just to get some extra A. I was taking extra B's and C because I'm quite a hyper person so I thought these are stress vitamins, I could use these. But only to that extent".

Concoctions, a subcategory of natural ingestibles, consisted of a liquid base, usually water or fruit juice, with other liquids added was noted by several respondents. This other liquid may have been alcoholic or nonalcoholic. A cider vinegar, with or without honey, was most frequently noted. Black strap molasses and a blend of sulfur and gin were also cited. One respondent, reporting knowledge of concoctions based on actual use of two remedies, noted:

R: "... I went blackstrap molasses, which was to help with the pain... Another one I tried was apple cider vinegar. I did drink that for quite a while and is not bad tasting".

Topicals

This category included remedies which were externally applied to the surface of body parts. The following table presents a summary of specific topicals cited by respondents.

| ALTERNATE TREATMENTS - TOPICALS | | | | | | | |
|---------------------------------|------------|----------------|--------------|----------|--------------|----------------|-----------|
| TYPE | TURPENTINE | MINERAL ICE | ALOE VERA | POULTICE | MUD BATHS | HOT SPRINGS | MOTOR OIL |
| RESPONDENTS CITING | 2 | 1 | 2 | 2 | 2 | 4 | 9 |

Table IV

Turpentine was reported as being applied either as the sole ingredient or blended with another substance. One respondent reporting knowledge of it which may have involved

some personal experience:

R: "... He had arthritis and they swear by this stuff that he mixed up to put on my knees and my sore hands - linseed oil and turpentine and something else. Oh it stunk ..."

Poultices consisting of different ingredients such as mustard or bread and milk were noted. Respondents noted the use of poultices had been a past practice in the family of origin but whether as a specific treatment for arthritis was not stated.

Mud baths and hot springs were indicated by several respondents. As with many of the alternate therapies or remedies reported, explicit commentary was not made as to whether the therapy had been used or whether knowledge remained only secondary.

A respondent expressed knowledge of hot springs and noted that while they had not been tried as yet, the respondent "hoped one day to go".

Motor oil was the topical remedy cited most often by the respondents. It was also revealed that those who had knowledge of it, had not used it. A respondent addressed the rationale for potential use and noted:

R: "... on the radio just a few weeks ago [someone] called the station ... about W40, the oil you put on hinges of the car to loosen them up. To loosen up the joints. It penetrates the skin or something. But can you imagine putting W40 ...".

Knowledge, of motor oil for these respondents was related to the specific action of lubrication of the joint required for

the desired outcome of improved joint movement. Several respondents expressed some reservations about its use.

Nonconventional Pharmacologic Agents

These agents were cited by half (n=9) of the respondents. This category has been designated as such because ingredients in the remedies, while recognized conventional treatment modalities (such as steroids, diuretics), are not in amounts or combinations recognized or sanctioned by government bodies legislated to authorize their use. (See table below for specific examples and number of citations). While antibiotics have been authorized for the treatment of infections, their use for the specific treatment of R.A. has not been sanctioned. As such, they have been included in the overall category.

| | ATM's - NON CONVENTIONAL PHARMACOLOGIC AGENTS | | | | |
|--------------------|---|---------------|--------------|-------------|-------------|
| TYPE | CHINESE CURE | MONTREAL CURE | MEXICAN CURE | EPSOM SALTS | ANTIBIOTICS |
| RESPONDENTS CITING | 1 | 3 | 2 | 1 | 2 |

Table V

Mexican and Montreal "cures" were reported and were recalled as having a cortisone base. Respondents reported a knowledge of it but generally without an indication of its use. One respondent noted:

R: "... There was also a Mexican cure and I don't know much about it, but I do know someone who took it and was in the hospital because of it. And that was almost the same as the Montreal cure, except

they added two other things. Yes, with the cortisone base".

More than half of the respondents reported awareness of nonconventional-pharmacologic agents or remedies. This knowledge was not reported as being a result of personal use of any of the agents.

Psycho/spiritual Modalities

This category included activities or treatment means which incorporated or focused on the mind and its mental processes or on the spirit to facilitate healing or achievement of an improved state of health. Half of the respondents indicated a knowledge of this category of treatment. The knowledge of some of the respondents was based on actual use. (See table below for specific examples).

| TYPES | ATM's - PSYCHO/SPIRITUAL MODALITIES | | | | |
|--------------------|-------------------------------------|------------|---------|---------------|--------------|
| | MEDITATION | RELAXATION | IMAGERY | FAITH HEALING | AURA THERAPY |
| RESPONDENTS CITING | 5 | 1 | 1 | 1 | 1 |

Table VI

Meditation was noted most often (n=5) with the majority who cited it having practised or used it. Positive mental imagery was indicated by one respondent as a means to combat the arthritis. This involves the use of the imagination and the centering of oneself. The respondent reported:

R: "I still think that there is this part of me, my faith sort of or whatever, that I think that the answer is in me somewhere, wherever that is that comes from just sitting and relaxing, thinking or

whatever. I love to think sometimes of my body chemistry working in the right way and washing out the arthritis ...".

Faith healing and aura therapy were cited by few respondents. One respondent, reporting having tried aura therapy on arthritic knees at one point, indicated "you're moving this current back into rhythm" as the basis of therapy.

Miscellaneous Therapies

The final category or grouping included a considerable variety of modalities reflecting different potential means of achieving sought outcomes. Some therapies involved direct contact and manipulation of specific or relevant body parts. (See table below for specific examples). Regarding massage, one respondent noted, "... I haven't been to any massage for fear of maybe hurting my arthritis. I believe more in physiotherapists if anything ...".

| MISCELLANEOUS ALTERNATE THERAPIES - A | | | | | | |
|---------------------------------------|---------|------------------|-----------------|-----------------|------------|------|
| TYPE | MASSAGE | CHIRO PRACTOR | REFLEX OLOGY | ACUPUNC TURE | TAI CHI | YOGA |
| RESPONDENTS CITING | 6 | 9 | 6 | 6 | 1 | 2 |

Table VII

Another respondent indicated knowledge, but not actual use of chiropractic. Several respondents reported knowledge of reflexology with none indicating knowledge gained from actual use. One respondent with a knowledge of yoga reported using it in a modified way:

R: "... When Kareen's yoga was on T.V. I used to do that although not all the positions, but just the hand movement and the slowness of the breathing would help me so much ...".

Respondents also reported knowledge or use of other miscellaneous remedies or therapies which were essentially external to the individual. These included cold room therapy, sitting in a uranium mine, use of a gold bracelet, a magnet or a copper bracelet. (See table below for number of citations). Some Respondents indicated knowledge of several of the above therapies.

| MISCELLANEOUS ALTERNATE THERAPIES - B | | | | | |
|---------------------------------------|-----------|--------------|---------------|--------|-----------------|
| TYPE | COLD ROOM | URANIUM MINE | GOLD BRACELET | MAGNET | COPPER BRACELET |
| RESPONDENTS CITING | 1 | 4 | 1 | 1 | 13 |

Table VIII

Copper bracelets were cited most frequently by respondents after cod liver oil. One respondent noted the copper bracelet was worn, not as therapy, but rather as jewellery. Comments by the other respondents indicated a superficial knowledge of copper bracelets as a modality. As one respondent noted, "well they always have these things about bracelets, yes copper and things like that ...".

In summary, all respondents had some knowledge of alternate treatment modalities (ATM's). Comments by the respondents indicated that the majority had knowledge of various modalities which was not based on actual use. The

category of the natural ingestibles was cited most frequently by the respondents, with cod liver oil being noted by a majority (n=15). This category contained modalities which were reported most often by respondents as being tried at least once. The psychospiritual category was reported by several respondents with knowledge tending to be based on personal experience. Knowledge of ATM's tended to be, on the whole, superficial and not a result of personal experience but rather from other secondary sources. These sources as revealed by data analysis, are considered.

Knowledge Source of ATM's

Knowledge or information concerning alternate treatment modalities came from various sources. Knowledge came directly or indirectly from professionals and nonprofessionals. As well as professional practitioners, the Self Help Group (SHG) was also noted. (The SHG is aligned with the conventional systems in reporting of the findings because of its apparent tendency to rely on the conventional system as a source of guest speakers and of written resource materials). Nonprofessional sources included members of social groups such as family and friends, various kinds of popular media, and alternate practitioners. (See table below for examples of professional and nonprofessional knowledge sources).

| | |
|------|--|
| | KNOWLEDGE SOURCE - A |
| TYPE | PROFESSIONAL |
| | G.P., Specialists, Therapist, Nurse, Social Work, Arthritis Society, Self Help Group |

Table IX

| | | | | | |
|----------------------|-------|-------------------------|-------------------------|----------|--------|
| KNOWLEDGE SOURCE - B | | | | | |
| NON-PROFESSIONAL | | | | | |
| FAMILY | MEDIA | FRIENDS & ACQUAINTANCES | ALTERNATE PRACTITIONERS | SALESMEN | OTHERS |
| 3 | 12 | 6 8 | 1 | 2 | 8 |

Table X

Professional Sources

A majority of respondents (n=13) identified professionals as direct or indirect sources of knowledge concerning ATM's. These professionals identified by the respondents included physicians, social workers and "professional studies" which were produced and disseminated by professional groups associated with the established conventional health system.

Some respondents identified knowledge about ATM as coming directly from the physicians. One respondent spoke of the warning offered by the physician which provided guidelines by which to assess possible treatment modalities. The respondent noted:

R: "... There are always a lot of grand recipes and ideas and I think, but your own doctor will tell you if some single thing works and it is not harming you and if it is not costing you a fortune, then go for it. Yes, it is my GP, both of the

doctors telling me that. We have been warned about quack medicine".

One respondent (n=1) identified a social worker as a source of knowledge. This information did not take the form of a warning, but rather was in the form of a suggestion for therapy. The respondent recalled:

R: "I had a woman in social work ... she mentioned massage therapy. She was taking massages just for her own stress. She had recommended it to me and said that she had got a lot out of it ...".

The respondents' comments indicated the role which health professionals generally play in acting as indirect sources of knowledge concerning alternate modalities.

Data analysis revealed that half of the respondents (n=9) used validation by conventional system health professionals as a source of knowledge concerning ATM's generally or specifically.

For one respondent, the advice sought was more of an anticipated rather than actual nature. The respondent noted:

R: "... Somebody with some authority would have to prove to me that somehow that was really an anti-inflammatory for instance and that it was a good analgesic and that I could use this instead of entrophen".

One respondent (n=1) indicated knowledge of a specific ATM through personal use and from having received validation of the modality by the physician. "I was telling Dr. [X] about taking the cod liver oil and he said, well you know they did think now that they help".

The Arthritis Society was also reported by a few of the

respondents as a source of knowledge concerning ATM's. As one respondent noted, "...Well, the Arthritis Society usually knows pretty well ... They keep an eye on all this". Data analysis revealed that most of the respondents turned to the Arthritis Society as a source of information about the disease condition and its management rather than as a source specifically and directly for information about alternate modalities.

The Self Help Group was identified by a few of the respondents as a source of information about ATM's. Analysis of the data indicated that the group served more as a source of information about arthritis generally and its management by conventional treatment. One respondent was rather articulate in expressing the perceived role of the Self Help Group in disseminating information about different modalities:

R: "... Because I think that we have learned along the way that these are things that help some people that don't help others. We don't ever give a blanket endorsement of whatever agent or for something. It just doesn't work that way. We have reading material in our group that we had to take out of our library because we, and we have a pretty good overseer of our library, but things ... [pause] that you know we really don't think that we can endorse. So that we just take them out. Rather than having a big quarrel about things, just don't advertise them".

Non Professional Sources

Non professional sources of knowledge were identified also by a majority of the respondents. Family was reported by a majority of the respondents with both immediate family (parents, children, spouse) and extended family being

mentioned. One respondent noted knowledge derived from an immediate family member:

R: "... but my mother had done this and she bought me a book a long time ago and I can't remember what it was called, something about arthritis and cod liver oil and how it would make you feel so good ...".

Several respondents noted past health practices of an alternate treatment nature within the family of origin. This provided some knowledge of alternate remedies, but not necessarily about remedies specific to arthritis. A few recalled several remedies. No respondent indicated use, either currently or in the recent past, of the remedies since the diagnosis of R.A. had been made.

The media was the next largest category identified by the respondents. Media included electronic media such as T.V. and radio, and printed media such as books, journals, promotional pamphlets and the popular press. Television was indicated by several as a source of specific information. One respondent noted:

R: "There are so many things that come out. One time I watched a show where they had a bunch of people with arthritis running around a cold room and that was supposed to help them".

Radio was a source of general or specific information for many of the respondents. One reported it as a source for a specific remedy:

R: "Oh of course there was that Dr. Alexander who wrote a book about it [cod liver oil]. How did I find out? I heard about him through somebody. Then I heard him on the radio".

The printed medium was noted by several of the

respondents. A few indicated that information came from casual reading while others noted that specific information had been actively sought.

One respondent recalled:

R: "... I tried something different to help. I went and bought that Dale Alexander book and faithfully took his ... [comment trailed off] .. I got the book, read the whole book, bought this cod liver oil ...".

Friends and acquaintances were revealed to be a ready source of information. Most of the respondents did not indicate whether the information was solicited by themselves or not. One respondent revealed:

R: "... I was going through quite a bad period and I was bombarded and I would have people phone about soaking in mineral salt, or taking alfalfa tea, or doing this or doing that and when I didn't do it they had a feeling that I didn't want to be cured".

A few others reported the experience of also feeling overwhelmed with advice and information from others.

Alternate system practitioners and salesmen were also noted as sources. The experience of others was also noted as contributing to overall knowledge of alternate remedies. One respondent, who reported a perception of an alternate remedy as negative because of an experience attributed to another individual, noted:

R: "So what happens when you take these multivitamins? Actually there was a woman at the hospital who was taking multivitamins and she didn't tell the rheumatologist that she was taking them and he put her on some of the antiinflammatory drugs and she died".

The respondents reported having some knowledge of

alternate modalities or remedies and the majority (n=16) could identify three or more such modalities. The depth of knowledge concerning ATM's appeared to be primarily superficial with few elaborating on the reputed purpose or action of any specific modality. Several respondents reported knowledge based on limited personal experiences with most of these respondents having tried only one or two modalities. For most of the respondents, the source of knowledge was from both nonprofessional and professionals. Professionals, particularly physicians, served as a source of validation of knowledge related to alternate modalities. Alternate modalities would not appear to be a primary element in the self care used by the respondents in their management of the arthritic condition.

Efficacy of Alternate Modalities

Data analysis revealed that a variety of alternate treatment modalities had been considered by respondents in forming perceptions of the efficacy of the modalities and the alternate system in general. These perceptions tended to be based less on actual experience than the perceptions associated with the conventional system and its modalities. Fewer alternate modalities were reported by respondents and while many reported having tried at least one, the knowledge of many of the modalities was not based on actual experience which in itself may have consisted of single use only. Perceptions of effect were not stated for all modalities which

had been cited. Perceived efficacy emerged as a key theme with levels of satisfaction associated with consideration of the alternate system, its practitioners and modalities. Data analysis revealed considerably less reporting of perceptions of alternate system practitioners than was revealed with consideration of the conventional system. This no doubt reflects the limited contact which respondents reported having with these practitioners. Perceived efficacy was related also to patterns reflective of tangible factors and to a lesser extent intangible factors which contributed to some level of perceived satisfaction with the actual or potential modality. The tangible consisted of specific remedies or therapies while the intangible consisted of factors such as belief and trust.

Data revealed varying perceptions of the efficacy of ATM's. One respondent (n=1) unequivocally rejected ATM's and reported never having tried or used any since the onset of the R.A. Two (n=2) who reported not using any, indicated that they were willing to consider that there might be some benefit. The remainder (n=14) reported having tried at least one ATM with varying perceptions of effect reported. A negative perception of efficacy was indicated by many of the respondents, with several (n=7) referring to ATM's specifically as "quackery". A majority of the respondents indicated a differentiation in the perceived efficacy which indicated a perception of potential usefulness of some degree.

Efficacy and Tangible Factors

A range of perceived efficacy was revealed concerning specific alternate modalities or ATM's in general. Perceived actual, or potential benefit or no efficacy and actual or potential risk were noted regarding natural ingestibles, topicals, pseudopharmacologic agents, psychospiritual modalities and other miscellaneous modalities.

Respondents comments concerning natural ingestibles indicated perceptions of efficacy ranging from benefit to risk. For a few respondents, perceived benefit and subsequent satisfaction was related to specific outcome. One respondent, commenting on diet related therapy, recalled:

R: "... After a while someone taught me about becoming vegetarian and he sold me on the idea ... I was on it for two years. It did keep me ... I was on this vegetarian diet for about, oh, five, six months. God it worked. My pain was, you know, not completely, but yes, I could walk again ... walk more comfortably ...".

Cod liver oil was reported by a majority (n=15) of the respondents, but not all had tried it. One who had tried and used it reported definite beneficial effect.

Another respondent, for whom the perceived effect was neutral, noted:

R: "... I tried cod liver oil for a while. But maybe I did not give it long enough. Did it help me at all? No, not really. Oh I gave it a few months of taking it every day ...".

For one respondent who reported a negative perception related to cod liver oil, this perceived effect was not related to an effect on the R.A., but rather to a foul taste.

A range of perceived benefit and negative affect was reported with other natural ingestibles. Cider vinegar was reported as having been used by several respondents (n=3).

While a few respondents had positive or neutral perceptions, some respondents (n=2) reported a negative effect based on experience. It was noted:

R: "Cider vinegar and lemon juice or honey and anyway I tried that ... but anyway I got really bad. After that my muscles just seemed to tighten up and I got really bad and I think it was too much acid with the aspirin maybe ... so I quit taking it".

Some respondents held negative perceptions of efficacy concerning the use of vitamins. These negative perceptions were based on perceived risk with two respondents reporting concerns associated with large doses of vitamins. For one, vitamins were acceptable if they were "more to the norm, not like the 2000 mgm of vitamins C per day".

Herbal remedies, such as camomile, alfalfa or ash leaf tea produced similar perceptions of little, no effect or potential harm by the respondents. Those respondents who had reported trying one or more herbal remedies generally had done so in the form of a tea. A neutral affect was reported by one respondent who reported the use of ash leaf tea for two years and noted, "it didn't make me feel any different". Subsequent comments by the respondent revealed an overall perception of neutrality concerning remedies in the alternate system. The respondent revealed:

R: "Most of them were a long time ago. They were after I was starting to get better ... I don't

think I would do any of those things either ... because I really don't think they are going to change much ... I don't think they are going to do anything for me. I don't think they are going to hurt me. I almost think its a waste of time to take them or do them".

Data analysis revealed similar findings when those remedies categorized as topicals and pseudopharmacological agents were considered. Perceptions of efficacy concerning topicals tended to be more negative (n=7) with few reporting limited or neutral affects (n=2), or, a positive effect or benefit (n=1). One respondent reported a benefit and indicated experience with a poultice which had been a home remedy in the family of origin and which had proved to be beneficial in managing an aspect of the arthritis. The respondent noted:

R: "I know what I used. I used my mom's poultice ... It cleaned it out. When I had the ulcer on my foot it would keep closing over ... and I put on my mother's poultice. It kept it open and it worked and it didn't close over and it took a whole pile of guck out of it ...".

The same respondent reporting a perceived limited benefit from another topical remedy turpentine which had been tried noted, "I did think it was better, but it wasn't no absolute miracle".. A negative perception was also reported associated with it ("Oh, it stunk"). Both resulted in a lack of satisfaction with the particular alternate modality.

Motor oil, as an alternate modality, was also considered by many of the respondents in a negative rather than positive light. One respondent perceived that there might be a

possible limited benefit based on rationale for use. As the respondent noted:

R: "... So maybe this is the idea, that we need [lubrication]. ... It might be o.k. if you have something on the surface, like something sore and swollen, but I can't see how it is going to get to the source of this. Well, you know with R.A. is the synovial lining. I can't see how it is going to work on that lining and in the damage that has been done. So it might be a good lubricant, but I can't see how its going to get in far enough to do anything".

Another respondent indicated the potential risk involved by noting, "I think it is next to committing suicide".

Consideration of nonconventional pharmacologic agents produced similar findings with two respondents (n=2) considering antibiotics to be of essentially neutral benefit while the other "cures", such as the Montreal and Mexican were perceived to have a negative or harmful effect, and, hence, be a risk. The neutral effect of antibiotics was attributed to the disease going into remission or the body becoming accustomed to the medication and eliminating whatever benefit might have been associated with it.

Data pertinent to modalities considered in the miscellaneous category revealed similar findings. Individuals tended to have perceptions of efficacy which were not always based on personal experience. A majority of respondents (n=14) indicated knowledge of copper bracelets, but all did not indicate whether the copper had been tried in an effort to manage the arthritis and what the affect had been. Respondents who had tried the copper bracelet indicated

perceptions of neutral benefit in which "nothing happened" and the respondent reported feeling neither "better or worse". Another respondent spoke of the copper bracelet as "garbage".

Reported perceptions by respondents produced similar findings concerning the efficacy of reflexology with varying effects being reported. As one respondent noted:

R: "I heard of people who had gone to them ... Like I know what is happening inside my body and I find it very hard to believe that it can help that much".

The same respondent also indicated a negative perception which was related more with an intangible factor rather than the tangible specific modality, reflexology. The intangible factor concerned the interpersonal skills of the alternate practitioner who was "rude on the phone. Like he felt like he was doing me a favour".

Acupuncture and chiropractic were modalities which were identified by many of the respondents. Acupuncture was perceived by a few to have a beneficial effect. Interestingly, those (n=2) who viewed the treatment as beneficial had used it. Of these, one noted the benefit was temporary and noted that adherence might have given longer term relief. Those (n=2) who perceived the method as a risk had not used it. One noted, "I've had enough needles punctured into me".

Chiropractic which was seen by one respondent as potentially beneficial, tended to evoke more of a negative perception in others which tended to be based on perceived

risk or harm. One respondent suggested:

R: "I had gone to a chiropractor, but not for my arthritis, I don't think that I would have gone to him for arthritis treatment simply because I didn't feel that there was very much that a chiropractor could contribute because I was aware that an inflammation in the joint was not something that you can put back into place. So I had no thought of going to him for arthritis".

Massage therapy on the other hand tended to evoke a more positive response when perceived efficacy was considered. Several respondent (n=6) had made note of massage during their interviews, with all but one tending to see massage as providing potential benefit of some kind and to some degree. One respondent saw potential harm and feared that massage would hurt the arthritis. Another indicated massage had not been tried, but perceived that it could have potential beneficial affect and noted:

R: "I've never considered it, but I would have absolutely nothing against it. It's one of those things that I'm sure it would certainly relax you and make you feel better. It certainly wouldn't hurt you.

For another, the ability of the treatment mode "to bring down your stress level and to create as little stress in your life as possible" made it worth considering.

Several found benefit in considering the mind-body connection, and perhaps in trying psychospiritual modalities. Some respondents who indicated a negative perception and apparent rejection of mind type therapies were in actuality denying the efficacy of specific modalities such as faith healing.

One respondent indicated experience with relaxation and positive imagery which had produced beneficial results and which could be used to help an individual cope with the R.A.

The respondent noted:

R: "I still think that there is a part of me, my faith sort of or whatever, that I think that the answer is in me somewhere, wherever that is, that comes from just sitting and relaxing, thinking of whatever. I love to think sometime of my body chemistry working in the right way and washing out the arthritis. I really think that helps me. That may work, who knows ...".

This importance of the mind-body connection and its potential benefit was noted by one respondent who indicated the perceived benefit which could be gained:

R: "Well I was just going to say that I firmly believe that R.A. or its onset for that matter, or even aggravation stems a lot from the mind and I was thinking that a lot of my pain and swelling and discomfort and the way everything has been going crazy in my life does not stem from a particular drug not working. Maybe a lot of it stems from my own mind and maybe my non-acceptance, my attitude and things like that.

Efficacy and Intangible Factors

This intangible concept of belief and attitude or mind set was reflected in the comments of many of the respondents, either as direct or indirect statements. Belief was expressed by some of the respondents in some aspects of specific alternate modalities. Alternate modalities, in which the individual plays an active part and uses the self in a holistic, way had some perceived benefit and hence value. Several (n=4) indicated a willingness to consider or support an alternate modality in which the mind or a belief in self

played a part. One respondent considered this and noted:

R: "But you know what I had. I had the belief in myself at that time. I felt at that time I had put more of my life together. Like I feel now.

Perceptions of benefit and risk associated with various alternate modalities were revealed by respondents' comments. Data also revealed that a positive perception of alternate modalities tended to be selective rather than comprehensive and tended to focus on the psychospiritual component. From none of the respondents was there unequivocal support for alternate modalities. A majority (n=12) indicated an explicit lack of belief in alternate modalities. This non-belief, and hence tendency to view ATM's as non efficacious applied to either specific modalities only or to alternate modalities generally. As one respondent noted, "well, I don't believe in it, but I haven't tried it either".

A perception of potential or actual harm or risk was a repeated refrain in the respondents' consideration of the alternate system, its practitioners and modalities. While there was a potential for belief in the positive affect of ATM's, the perception of risk mitigated against an acceptance of or a belief in alternate modalities for many of the respondents. For one respondent, for whom the risk or perceived negative affect was viewed as psychological, noted:

R: "I don't think that a lot of these kinds of things are going to hurt you like the copper bracelets but on the other hand I don't want to get my hopes up either, that this is what is really helping and then have it all fall down again. Because I think if you do that you are likely to be in a better

depression ..."

A few respondents essentially rejected ATM's either specifically or generally and noted the role that belief and the power of the mind could play in producing perceptions of benefit or relief from symptoms. One respondent noted:

R: "I just really feel that the most that these things do, if they do anything at all, is in the person's mind. Because arthritis comes and goes I think that it is quite possible that you think they give you some kind of relief ...".

A clear majority of respondents perceived some if not all alternate modalities in a negative light. Several considered ATM's to be "mumbo jumbo", "garbage", "fringe" or "hoaxes". Almost half (n=7) used the terms "quackery" or "quack" at least once during the course of the interview. For some it was a general reference to alternate treatments.

Only one respondent attempted a definition of quackery and quack substances. The concepts expressed by the respondent were comprehensive and tended to reflect the comments of other respondents as well. The respondent noted:

R: "Quackery? Well, it pretends to advertise or elaborate on some treatment which is unethical, I suppose. Yes, some treatment that promises a cure or near cure ... There is very little basis for it of course, they want some kind of remuneration for it. And quite handsome remuneration".

The overall perception of ATM's was one of no benefit or even potential harm, and, with the exception of the psychospiritual modalities, little credence given to beneficial effect.

Another intangible factor related to the respondents'

perceptions of the efficacy of alternate modalities was that of the motivation of the alternate system practitioner. Respondents' comments tended to indicate a perception of alternate practitioners having a goal only of financial gain rather than a desire to help. This was compounded by the perception that alternate modalities had no benefit. As one respondent stated it, "I guess it is just one of those kinds of cures. Yes, the cures that aren't cures". This scepticism concerning the ability to cure was also expressed by several other respondents.

The perceived negative motivation of only wanting to gain financially put the alternate practitioner and the modality in a negative light. One respondent noted that:

R: "... If somebody really and truly, was a doctor and had really cured arthritis he would make this available without people having to go down there and having to order it".

Despite this, not all respondents rejected alternate modalities outright. Only one rejected ATM's without hesitation, noting that there was enough pain with trying "extra stuff like that". Rejection was also based on the respondent's trust in the medical doctor and the health care system generally. The majority (n=13) tended to differentiate in their perception of the efficacy and value of alternate modalities. For some, differentiation was based on the absence of harm produced by the treatment. If no harm would result than it was not rejected and was considered as a possible treatment, although not necessarily by that

individual. For others, differentiation was based on perceived potential or actual benefit received from trying it. Whether a treatment worked inside or outside the body was a determining factor for some respondents when considering efficacy. For others, efficacy on the inside was related specifically to a mind-body relationship. Although the majority differentiated to some extent, the overall perception of the efficacy of alternate modalities was one of, to a lesser degree, limited benefit, and to a greater degree, one of no effect (neutral) or potential negative effect. (risk)

Factors in the Use of Alternate Care Systems

A purpose of the study was to determine the perceptions which individuals with arthritis had concerning the use or adherence to alternate treatment modalities. Research questions sought data on what alternate modalities individuals used to manage the R.A. and what experiences with R.A. prompted consideration and use of the alternate systems, its practitioners and modalities. For this study, use has been considered in two senses. Use has been considered in the sense of an initial exposure to or trying of a modality and in the sense of a decision to use it on a more ongoing basis. Data revealed that in contrast to the consideration of the conventional health system, respondents tended not to turn to the alternate system initially for education concerning the R.A. or for the treatment which might be used. Data also revealed that all respondents (n=17) had knowledge of some

ATM's and that a majority of respondents (n=14) had tried at least one alternate remedy once during the course of the arthritis. This trying of one or more alternate modalities over varying periods of time contributed to a perception of the efficacy of alternate modalities for many of the respondents. Data also revealed that respondents tended not to use ATM's to manage their arthritis and those who did use or had used, tended to do so in a conservative, sporadic and short term manner.

Analysis of the data revealed a variety of factors related to the respondents' use of alternate treatment modalities. These factors may be considered under the overall theme of treatment selection and use. Patterns which emerged within this theme included respondents' perceptions of benefit versus risk associated with ATM's; belief and trust; disease condition; validation; support; cost; time, and remission. As emerged with the consideration of CTM's, benefit/risk and belief and trust were revealed as key factors in the respondents' decisions to use or not use the alternate system, its practitioners and modalities.

Benefit/Risk

Reported perceptions of the respondents revealed the benefit/risk category in the responses of all of the respondents (n=17). All cited a perception of some degree of risk associated with alternate modalities, whether an alternate modality had been tried or not. There was an

orientation to perceiving alternate modalities as more risk than benefit producing. While several respondents reported actual or potential benefit from specific alternate modalities, the majority reported a perception of no effect or of risk. Overall perceptions of risk were reflected in the respondents' use of such terms as "dangerous", "awful", "bad taste" and perceptions of "being too chicken" and being "afraid" to try ATM's. Most respondents who expressed negative perceptions of effect noted fear of injury or further damage to the arthritis such as might occur with chiropractic.

For other respondents, it involved caution about anything that they took "inside" themselves. As one noted:

R: "I don't know if I would go to a point of trying something that you have to drink that I didn't know what was in it. I don't think that I would do that".

Many respondents expressed concerns about actual or potential harm from either specific modalities or alternate modalities in general. As one respondent noted:

R: "... Those are the kinds of things that I think people could get hurt by. That is why I sort of shy away from those things. There are those that might not do you any good, but they might not do any harm. Then there are those which may also do you harm. I guess maybe some people are more adventurous at trying these things, but I certainly am not".

A lack of willingness to use was based in their perception of the alternate systems and its modalities as "useless", as "quack medicine" or just "fringe" and for "flakes". One respondent noted that while alternates might

not "do anything", neither were they "going to hurt", and that it was rather a "waste of time to take them or do them".

A few respondents indicated some possible or actual benefit from the use of alternate modalities. Also, a few noted that specific alternate modalities had been or might be considered because of the low risk associated with them and from the benefit which could be derived. For several other respondents, benefit would have to have been related to a specific sought or desired outcome. One respondent noted that alternate modalities would be considered, ".. for pain control, yes, for getting rid of my arthritis, no".

The perceptions of the efficacy of alternate modalities ranged from some possible or actual benefit, through to perceptions which primarily reflected neutral efficacy and harm or risk. The decision for some to consider using them was based on a perception that some benefit would be achieved or at least, no risks or harm would occur. For those respondents who had not used or would not consider using ATM's, the decision was based primarily on a perception of the modalities, specifically or generally, being at best useless or at worst, harmful.

Belief and Trust

The importance of belief and trust were readily seen in the perceptions offered by the respondents concerning beliefs about treatment and expressions of trust (or its lack) in the alternate health system. Comments by respondents indicated an

overall lack of belief and trust in the alternate health system, its practitioners and modalities. All but two respondents noted either a rejection or nonbelief in alternate modalities, while noting a belief or a trust in the conventional health system. As one respondent noted, "I'm not discounting that they don't work for somebody .. it didn't make me feel any different".

The power of belief in perceived efficacy and hence a motivation for its use was noted by several respondents. One indicated, "I guess if I have the feeling that it is not going to work, then it is not going to work". The power of placebo affect, as well as belief generally in using a treatment modality was commented on by only one respondent who noted, "The placebo affect has got some measure of therapeutic affect. And if something is going to make you feel better, so what ... I wouldn't jump on top of something without first considering how the person really perceived it".

An expressed general nonbelief or nontrust in the alternate system, its practitioners and modalities was revealed also by the respondents as a perception of a lack of sincerity or of questionable motivation on the part of alternate system practitioners. One respondent expressed scepticism concerning motivation and noted, "If somebody had really cured arthritis he would make it available without people having to go down there". Another respondent noted that, "People buy these lurid titles about miracle arthritis

treatment". This indirectly points to the desperation individuals might feel in seeking out "miracle" cures.

Disease Condition

The disease condition and the desperation it created was not readily revealed as a factor in considering or using the alternate system or its modalities. While some respondents spoke of desperation, most did not indicate it as a reason for their trying a specific alternate modality. One respondent noted that if "trouble" (ie. no longer receiving benefit) developed with the current prescribed treatment, and the arthritis worsened, then an alternate modality might be tried. This particular respondent had tried a number (n=6) of modalities in the past, within the first four years of the onset of the R.A. Specific diet therapy, in the form of a vegetarian diet had been instituted in the hope of getting relief from distressing pain. The respondent also indicated having tried "blackstrap molasses" in an effort to relieve the pain. For another respondent, pain was a deterrent rather than a motivator to seek an alternate remedy. The respondent noted that there was already "enough pain" and an alternate modality might contribute to more. Other respondents reported trying specific modalities such as yoga but having to discontinue because of disease impact, resulting in an inability to do the positions.

The type of arthritis and the advanced stage of the disease was questioned by another respondent who noted:

R: "I also feel that these remedies only seem to work for the peripheral arthritis or people who have only got a little bit of arthritis".

A few respondents acknowledged feelings of desperation at different times in their arthritis experience, but essentially rejected the use of alternate modalities.

Several respondents reported use of alternate modalities at various periods in the course of the arthritis with varying degrees of benefit perceived. Data analysis revealed that disease impact and resulting desperation did not appear to play a key role in consideration or use of alternate remedies for a majority of respondents.

Validation

A majority of the respondents indicated a need for validation either through consulting health professionals or through personal experience. As one noted, "I am not the kind of person who is easily swayed - I need concrete proof of everything". The majority (n=11) used professionals at some level in the health care system to validate their knowledge concerning alternate modalities. A decision to use an alternate modality would not have been made by several of the respondents without professional validation. Some indicated they might consider use of an ATM if it had been "scientifically proven".

For some, validation, through personal experience was a factor in considering an alternate modality either as beneficial or for future use. One respondent speaking of cod

liver oil noted, "well, I don't believe in it, but I haven't tried it either ...". It would appear that validation by health care professionals was more of a deciding factor than was personal experience in considering use.

Support

Another factor which emerged from the data was that of support, which suggested assistance or help of some kind. Several respondents indicated, either directly or indirectly, the presence of support while others indicated a lack of it. For those indicating current support (n=2), it involved family members, who shared information and offered encouragement for using specific alternate modalities. One respondent reported:

R: "... Meditation had been suggested to me. One of my [relatives] suggested it. She is a great believer in that and has sent me articles ...".

Other respondents saw the influence of family and friends as less supportive. One indicated little or no use of home remedies during the growing years. Another noted that while some benefit had been derived from a particular topical concoction, the spouse found it offensive (odour) and its use was discontinued. Other respondents reported having relatives who did not convey empathy for the respondent's suffering with the arthritis and suggested the individual was not interested in improving. One such respondent noted:

R: "No, I know some of my [relatives] want me to try something and I say, oh, it won't do any good and they say I just think you like being sick. I say its not that".

Several respondents spoke of a general lack of

understanding of the arthritis condition by not only family members, but also by the greater community. Others spoke of being "bombarded" by remedies from friends and acquaintances, which in turn caused them to reject considering alternate modalities because of the pressure. Other respondents reported succumbing to peer pressure and trying a particular remedy which in turn produced some negative results. Some respondents perceived support for ATM use from family and friends. Others viewed suggestions from family or friends as non supportive in that empathy for the respondents' suffering was not evident. Overall, this contributed to a nonconsideration or rejection of alternate modalities for the arthritis management.

Cost

Cost emerged as a factor in determining whether the respondents would consider or continue using alternate modalities. It did not emerge as a factor in the consideration and use of CTM's. This, no doubt reflects the fact that all individuals in Canada are covered under government health insurance. Several (n=8) spoke of cost in their consideration of treatments. Some indicated a willingness to try it if the cost were reasonable enough. One respondent spoke of a willingness to take massage therapy "if in this very area there was somebody who was reasonably priced". For another respondent the financial resources were reported as limited and this was a factor. The respondent

noted, "... I've seen people spend a lot of money and you can't really blame them. But I never did have lots of money to spend". This idea of potential discrimination in access to treatment based on finances was echoed by another respondent, who note:

R: "... People who can afford these things, can get them and people who can't even try them because they can't afford them anyway. And I am not sure, that that is a good way to have things. I think that if it is going to help somebody then it should help everybody. Not just a chosen few, the ones who can pay".

Cost emerged as a factor with few respondents noting a willingness to consider or use alternate modalities if cost was not reasonable. Comments by respondents also indicated that cost should not be a deterrent to accessing desired treatment.

Time

Factors related to time since usage, duration of usage and time required to wait in order to receive treatment were noted by several respondents (n=8). One respondent noted that usage had occurred more than a decade before in the early years of the arthritis. The respondent indicated that actual time spent using the modality may not have been sufficient, and noted, "Talk about bracelet [copper]. That was in the early, early part and I tried one, one time. If you are going to try any of those things, I guess you would have to try it for quite a while before you would notice any change ...".

Another respondent spoke of time as a factor which

mitigated against trying a specific modality (holistic medicine practitioner) because the time involved in waiting for an appointment was too long. Several respondents suggested the necessity of trying an alternate modality for a period of time in order to assess its efficacy, but none reported having done or considered doing this with respect to alternate modalities. Comments by several of the respondents also suggested that the trying of various alternate modalities occurred well in the past, in the early years of the arthritis.

Remission

More than half of the respondents (n=9) reported the perception that beneficial effects attributed to alternate modalities may actually be due to the remission of the arthritis. Some cited the term specifically, while other alluded to it in a more indirect way. One respondent noted, "It is kind of hard to tell because I never know whether my body is some days you are good or bad and you don't know ". Another respondent suggested:

R: "if you understand that the disease comes and goes and recedes on its own ...[and] ... I think that its quite possible that you think that they give you some kind of relief ...".

Remission, then, tended to be viewed as a natural occurrence with the arthritis and was a way of accounting for any benefit which might have occurred with the coincidental use of an alternate modality. In this light, it becomes a factor in not considering an alternate modality for the

management of arthritis in self care.

Summary

In summary, it would appear that a variety of factors contribute to the consideration of use (or non-use) of alternate modalities. Various alternate modalities were reported as used (single time or more ongoing) by a majority of respondents. These included specific modalities which had been grouped in categories designated as natural ingestibles, topicals, pseudopharmacologic agents, psychospiritual and miscellaneous which included such modalities as yoga, chiropractic, copper bracelets by way of example. Consideration and use or rejection was based on several factors. Perception of potential or actual risk versus benefit and lack of general belief or trust in the alternate system emerged as key factors. Other factors which emerged and contributed to the decision to use or not use an alternate modality included disease condition, validation by health professionals, perception of support or its lack, cost of the alternate therapy, time given to treatment use and finally, remission of symptoms due to natural occurrences.

All respondents reported knowledge of at least one alternate remedy. Most respondents had tried one remedy at least once. The trying of an alternate remedy was reported as being in the past, early in the course of the arthritis and was of single or short term use only for many of the respondents. In general, respondents did not report a

perception of beneficial affect associated with alternate modalities, nor was there a reported perception of a belief or trust in the alternate health system and its practitioners. In conclusion, use of the alternate health system and its modalities by respondents was sporadic and conservative.

SELF CARE AND COMBINED HEALTH SYSTEMS

A purpose of the study was to determine the perceptions of the respondents with regard to use of the alternate health system as an adjunct to the conventional health system. A research question sought data on what value, if any, was given to a treatment combination consisting of conventional and alternate treatment. Analysis of the data showed that the majority of respondents did not use or had not used the alternate system as an adjunct to the conventional system in order to enhance the effects of treatment. All respondents had knowledge of various alternate remedies and a majority (n=14) had had experience with at least one alternate modality. This experience generally was reported by the majority as being limited to single use or use lasting only a very brief period. Some noted that actual or possible benefit could be derived from ATM's. A minority (n=3) indicated use of five or more alternate modalities over a period of time since the onset of the arthritis with most reporting use early in the course of the R.A.

Although some respondents had indicated some degree of support for or a willingness to consider alternate modalities,

only two respondents (n=2) reported an ongoing use of different alternate modalities. Both had reported some degree of benefit from some of the alternate modalities tried. One noted the rationale for using alternate modalities by stating, "nothing ventured, nothing gained".

One respondent reported use of alternate modalities over the years since the initial diagnosis of the arthritis had been made more than 15 years earlier. The respondent indicated a knowledge of a greater number of different modalities than many of the other respondents, reporting nine with eight of them having been tried. Personal experiences with alternate modalities had included cod liver oil, alfalfa tea, topicals, vitamins, diet therapy, faith healing, aura therapy and poultices.

Factors in Adjunct Therapy Use

Comments by the respondent revealed that dramatic results or outcomes were sought through the use of various modalities, whether conventional or alternate. The respondent reported a lack of dramatic results (ie. significant benefit) with the use of alternate modalities as well as conventional treatments. Several CTM's were reported to have had negative or no effect and few were reported to have had positive affects. The respondent indicated the desired outcome, pain relief, had been sought in considering or using either system's modalities.

The general impact of the arthritis proved a factor in

the consideration and usage of various modalities. The respondent generally described the arthritis as a "rotten thing to live with". Early in the course of the R.A. parenting of young children had been effected. Over the course, the ability to perform activities of daily living had been compromised. Physical impact with pain, deformity and ulcerations was noted most frequently by the respondent.

The respondent indicated, the conventional treatment for the ulcers was not a fully satisfactory one. The use of prescribed "compress" dressings had not promoted healing of the ulcers. Satisfaction in treating the ulcer was derived from the use of a past family health practice involving the use of a bread and milk poultice which "kept it open and it worked and it didn't close over and it took a whole pile of guck out of it". The use of the poultice was as a result of desperation and was a "last resort" to try and relieve the "agony".

Benefit and hence satisfaction had also been derived from the use of other alternate modalities for nonarthritic conditions in the past with good effect. Thus reinforcement for the perceived beneficial affect of alternate modalities had been made.

Although desperate at times and a "willing to try anything" attitude existed, some degree of caution prevailed in the respondent's consideration and use of alternate modalities, specifically with regard to ingestible modalities.

Cost was also noted as a factor in determining whether ATM's would be used and to what extent. Availability and convenience, also, were factors in this respondent's situation. The respondent noted the importance of exercise, a conventionally prescribed treatment, and expressed a perception of a lack or at a limited resources which could be accessed on a regular basis.

A final factor in the respondent's decision to use or not use various conventional and alternate modalities was that of individual preference. As the respondent noted:

R: "I would think it is something that you have to try. You have to decide if you want to just stick to prescribed medicine ...", [particularly if] ... "somebody is doing something and it helps ...".

The other respondent indicated a more continuous, on going use of at least one alternate modality in conjunction with conventional treatment. The respondent related not only a long time practice of trying ATM's (approximately 15 years) but knowledge of a fairly large variety of different modalities. The respondent had noted, "all different things I tried that people were telling me". Desperation related to disease condition was not revealed as a key factor. While the respondent noted that ATM's were not used to desperation concerning the arthritis, nonetheless the arthritis was reported as having an impact on a variety of areas in the respondent's life, notably socialization, recreation, occupation and the biological realm. The respondent noted the arthritis was "no worse than usual", but thought the

remedies "would help my knees". Consideration of the data revealed that almost all alternate modalities used were treatments in the natural ingestible category, such as epsom salts, herbal and alfalfa teas, garlic pills, liquor concoctions and cod liver oil pills and liquid. These tended to reflect substances which the respondent reported perceiving as "something I knew wouldn't hurt you like". The only other modality cited as being used was a copper bracelet which was reported a producing no effect but a "dirty mark" on the arm. Use of ATM's generally were reported as producing neutral effects with some described as "useless". One alternate modality, cider vinegar, was noted as producing a negative effect resulting in its discontinuation. The cod liver oil was the only one reported to have produced any benefit reflected as joints reported as being not "quite as bad" and dryness of eyes having been relieved. The respondent also noted that the cod liver oil had been used for approximately a year and a half and had been temporarily stopped about a week before the interview due to the particular brand not being available. When asked if consumption would resume the respondent noted, "Well, yes, if I can get those other capsules. I think I will. It's a lot easier to take it in capsules than off the spoon cause everything smells like fish around here".

This respondent had derived more perceived benefit from conventional treatments. Treatment had consisted of

medications, surgery and particularly exercise with each having produced at least some benefit. A variety of prescribed medications had been used over the years with most producing limited or no effect. As with use of ATM's there was also the consideration of risk or potential harm with convention drugs which were being taken or were being considered. The respondent noted:

R: "Well, sometimes if I think they were going to help me it would be a thought and then I hear how other women talk about how their stomach rots ... they can't eat this and that and they're on these other drugs, so I think its better not to take them".

Data analysis revealed that the respondent had a belief and trust in the medical health professional and this was a factor in considering whether further treatment would be considered. The importance and valuing of exercise was emphasized by the respondent. The respondent had also identified that the use of cod liver oil had resulted in the joints, so necessary for activity, as not being as bad. Thus, reinforcement for the use of alternates as an adjunct to conventional modalities was obtained through personal experience.

The respondent did not perceive any difficulty in using adjunct therapy. This was particularly so if little or no risk was involved. Lack of adherence to the prescribed treatment was seen as being more problematic, with the respondent noting:

R: "Well, like the doctors always say. They don't like you trying other things because you quit

taking your own, the ones that they prescribe to you. But I never quit taking the ones. I took them right along with what I was trying. ... well, there really wasn't any drugs. Just the epsom salts and I figured it wouldn't hurt to take them along with my drugs. Enough to cover a dime and the copper bracelet wouldn't hurt anything. The only thing that was really was the cider vinegar thing".

Consideration of the data reveals the use of adjunct or combined therapies as being very limited among the respondents. For those few respondents who had tried and used alternate modalities in conjunction with conventional, a variety of factors were involved. Perceived benefit of some degree was noted as a factor in continuing the use of an alternate treatment. Dissatisfaction with conventionally prescribed treatment was not revealed as a key factor in turning to alternate modalities. The small number of respondents who reported a combination of conventional and alternate modalities is a reflection of the overall minimal usage of alternate modalities displayed by the respondents who participated in this study.

SELF CARE PATTERNS

Data was obtained from each respondent concerning specific and general self care practices. Data obtained from respondents revealed a ready acceptance of the conventional health systems and its practices, and a limited, often cautious or sceptical acceptance of the alternate system, and its various practitioners and modalities.

Consideration of a health system to enhance self care

agency (capability) was determined in part by the respondents' assessment of self care in the three requisite areas of universal, developmental and health deviation needs. The impact of the arthritis produced deficit for self care which necessitated the turning to a health system for information about the condition and means to manage it effectively. Data revealed that nonprofessionals were also sources of information. All respondents reported having used the conventional health system, its practitioners and modalities extensively and more consistently. A majority of respondents had reported knowledge of and had tried at least one alternate modality as a self care practice in the arthritis management. This trying was limited to single or very short term use and hence use of the alternate health system, and was much less pervasive than with the conventional system. This use of the conventional system with a lesser use of the alternate system is reflective of the self care practices of the respondents. This self care, as reported by the respondents, is reflective of a mutual therapeutic self care determined by each respondent in which another system or systems was/were used as well as the self care capabilities which each respondent brought to the self care.

Self Care and Coping

This mutual self care, evident in the comments of the respondents, reveals the final theme of coping as means to live with and manage the arthritis. Coping, as elaborated

upon by Monat and Lazarus (1985) "refers to efforts to master conditions of harm, threat or challenge when a routine or automatic response is not readily available" (p.5). The theme of coping may be further differentiated into the patterns of self reliance and other reliance with other reliance being further categorized into reliance on professional and nonprofessional sources. This reliance on others reflected support from others as well as a reliance on the conventional health system. Reliance on self tended to reflect intangible factors such as pacing, comparing, attitude or perspective, achieving, prioritizing, having other interests, information seeking and self responsibility. Although reliance on the conventional health system and its modalities was revealed, there was equal evidence to support an extensive use of coping strategies focusing on the self.

Coping and Reliance on Others

Data revealed that two categories of reliance on others, namely professional and nonprofessional emerged as used and relied upon by the respondents. Professional categories included specific health professionals as well as specific professionally based programs such as Home Care. One respondent noted that Home Care had done "wonders" in the respondent's ability to manage daily life and activities. A few respondents identified the support received from health professionals and which had "meant the world" to them. In considering reliance on the conventional system, its

practitioners and modalities many also expressed the positive, long lasting benefit which had been received from conventional modalities such as surgery. Some respondents (n=4) cited an anticipation of future surgeries for an expected deterioration in condition. Chemotherapeutics (modalities) were also cited by a number of respondents (n=9) as being necessary to either control pain or to prevent or control flare up symptoms. The reliance on chemotherapeutics was summed up by one respondent who noted, "You've got to go with something. You can't just push all that medicine aside and you can't live without it anyway". Several respondents indicated an indirect reliance through their need for information initially concerning arthritis and its management and for professional validation of treatment information particularly concerning other health care systems. The perception of no alternatives, reinforced the reliance on the conventional system and its practitioners. One respondent noted, "... when you really need a doctor ... yes, for emergencies or when you can't do anything and you don't know where else to turn". For many, reliance was reflected in the sense of belief and trust in the external other of the conventional health system and its practitioners and modalities.

Respondents also expressed a reliance, to a greater or lesser degree on nonprofessional sources, with a majority (n=11) indicating experience with support received from others or a reliance on resources of some kind. For one respondent,

it was support available in the occupational setting when time could be made up with the aid of fellow workers who could help carry heavier items. The Wellness group sessions were noted by another respondent who indicated that increased assertiveness resulted which was "fine when it was happening [ie. the program], but when you are not going to this thing all the time ... after you stop going you tend to go back to the same old thing". Family and the Self Help Group tended to be cited more frequently as examples of support. One respondent noted a relative who was a "great encourager". Another spoke of other family members to whom tasks could be delegated. Yet another respondent spoke of a friend who offered support with family responsibilities and who "did the things with [the children] that I couldn't" and who was a "true friend". For other respondents, the reliance on others took the form of the activities and socialization associated with a crafts group. One respondent noted S.H.G. provided a place to talk and:

R: "... [to be] with people who have had similar experiences, or people who got worse, or about to have surgery, ... some of them are getting different things. It's very helpful. I think its very encouraging to meet somebody in the group who has it in a bad way and who has gotten some relief".

Coping with arthritis through a reliance on others involved contact with both professional and nonprofessional sources.

Coping and Reliance on Self

All but one respondent (n=16) reported at least one coping strategy employed which exhibited a reliance on self. Consequences of not pacing were also noted by some, with one respondent stating,

"... you think, oh, I'm going to do this or that and you go ahead and do this, that and the other and you pay for it. You've got to learn to spread things out, yes, to pace yourself".

A couple of respondents (n=2) indicated prioritizing as a coping strategy. One respondent noted,

"Before I had my arthritis attacks, I would do my household chores ... all in one day ... I changed my shopping habits then. I shop maybe 2 or 3 times a week and I don't carry loads. I have a little shopping cart of my own that I use ...".

The use of specific techniques such as stress management in the form of relaxation was noted by a few respondents as a means of managing. One respondent indicated the use of humour to cope by reading every funny book that could be found. Also mentioned were coping through modification or adjustment of lifestyle, with one respondent noting modifications having been made in the home environment to make things "easier" and "to avoid the strain". Comparing was another category revealed and was used to ease the impact of the arthritis. For one respondent, the comparing served to build hope and encouragement. The respondent revealed:

R: "Just from meeting some of the people who had the arthritis and who had somewhat of a recovery and I think that that gives you some encouragement. You also realize there are people who are continuing to cope who are in poorer health than you are, so if

they can do it to some degree, you can do it ...".

Shift in attitude or perspective was identified most frequently by a majority (n=12) of the respondents. Many expressed the sentiment of not wanting to focus only on the arthritis, and as one respondent noted:

"I try not to separate myself into arthritic group and non-arthritic group and only an arthritic group can understand me ... I try to put all that into perspective. There was probably a time when ... arthritis was the MAJOR thing in my life, but now I don't see it as such a major thing ... I began to see that there was something. I wasn't just a bunch of achy bones ...".

For another respondent, having a chronic illness meant becoming more "understanding" and "patient" as a result of always having to wait to get help to get things done. For another, "optimism" had to be there particularly when the uncertain nature of the arthritis with its potential exacerbations was considered, and noted, "... I do think that I will have to start the climb again if it ever gets really bad again. I believe is a cyclical thing. I do know that there's arthritis and life ...". The putting of the arthritis into a holistic perspective was stated quite succinctly by one respondent who noted, "Because I really know that I have got arthritis and physically, other than the arthritis, I don't have anything wrong with me".

For others, coping was reflected in the pattern of acceptance. Almost a third of the respondents (n=5) indicated this as a means of coping. For one, acceptance meant "I think you have to resign yourself to the fact. Why be miserable

about it". For another it was recognition and acceptance of the fact that there was no known cure.

The desire to do was reflected in the patterns of achieving/accomplishing and having interests, activities and motivation. Almost half (n=7) indicated being able to achieve, accomplish or rise to a challenge as a means of coping and overcoming in the struggle with the arthritis. One respondent indicated,

"I guess what helped was I still succeeded in spite of what I had, because to be able to make the club ... despite the diseases, that was a great reward". For another it involved thinking "of the things that I can do rather than dwelling on the things that I can't do. I try to do anything that is going to boost my confidence ...".

The need for interests and activities other than those related to arthritis and having motivation or a reason for going on despite the effect of the condition were noted by half (n=8) of the respondents. One respondent recalled that through the post secondary education period "it was not bad and I think that was because I had a purpose and a goal and I was enjoying my studies". Getting out, going places, shopping, visiting family and friends were noted by respondents. One respondent identified having a "good social life" and "good home life" as important because "... if all these things bother you, you really don't feel very well. But if everything is going along good, you feel a lot better". Helping others was also noted by several respondents as being "part of my therapy for myself as I am not thinking about what

is wrong with me". Another respondent, for whom developing other interest was illustrative of having developed a new perspective or attitude concerning the arthritis, noted:

R: "... That year, say that I was so bad I don't think I ever talked about anything else. I was arthritic. There was nothing else in my life. Then once I realized I was going to get well, at least for a period of time, then I didn't want to talk about it in the group and stuff, but I don't talk about it all the time with my family or with my friends ... Talk to me about going to the States next weekend. I don't want to just talk about arthritis".

Attitude, particularly an acceptance of the limitations to function and self care capabilities was revealed as important.

A majority (n=10) also expressed the need for information as a basis for coping. Several indicated information seeking activities, while others indicated only information as a basis for action, but which was not necessarily a result of active seeking of information. To some respondents, coping meant needing to know "the outcome of this and what I can expect from it". Another respondent addressed using information to help alter the perspective toward the arthritis, and noted:

R: "... of course studying and reading all you can. You realize where you are at. Yes, it helped to demystify it for me in a sense".

Regardless of the source and the process for acquiring it, information or knowledge is an important factor in the self care capabilities and practices in the management of the arthritis condition.

Some respondents noted that while information was

necessary for decision making relevant to treatment, the decision was ultimately the responsibility of the individual.

One such respondent noted:

R: "... A decision is never made for you so You make the decision. And there is always somebody there who will talk to you and discuss with you the different avenues you could take and to sort of point out the different drawbacks and benefits of whatever that treatment is. I don't think anybody ever pushes on you something you don't want to do or that you don't think will be of any benefit to you ...".

Some respondents believed responsibility entailed ownership for actions. One noted, "... And my aches and pains are often my own fault. Because I am doing too much, I know, if I slow down, but for me psychologically it is not always the best thing for me to do ...".

The sense of mutuality or collaboration with the health practitioner was suggested by one respondent, who noted: "... As far as the mental part of me trying to get well that way, to help my body, I think the onus was definitely on me for that. That had to come from my own motivation and incentive and everything". For another, responsibility entailed asking, because "you have got to know how you feel. Yes, you have to let them know how the treatment are going". Finally, one noted, "I know I'm not responsible for having it, but I've got it and I think I'm responsible to deal with it. I mean I just can't pass it off to somebody else ...".

Summary

In summary, a variety of coping strategies are used to

cope with and manage the arthritis condition. These included categories which reflected the broader patterns of self reliant and other reliant strategies. The majority of respondents indicated as great a utilization of self reliant as of than other reliant strategies. Based on commentary by the respondents, coping strategies would be appear to be a fundamental component or element in self care management.

Consideration of the data reflects the major themes which emerged. The themes reflect the impact of the arthritis; the importance and components of knowledge in self care management; the selection and use of health care systems for the management of the arthritis and finally, coping strategies used to facilitate the living with and managing the arthritis experience.

Chapter VI

DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

Introduction

Health is viewed as a fundamental right of every human being. Self care in which individuals use "self assessment, self diagnosis and self treatment both to prevent and solve health care problems" is considered as one of the major means of achievement, maintenance and improvement of health. Individuals display variability in self care practices within the context of similar health deviation requisites or needs. A study was conducted to determine the perceptions of individuals with Rheumatoid Arthritis (R.A.) regarding conventional, prescribed treatments and alternate treatment modalities in the management and self care of arthritis.

The findings of this exploratory study are discussed in light of the conceptual framework and review of literature. Implications for health care providers delivering care to individuals with R.A. are noted and recommendations for nursing practice, education and research are identified. Limitations of the study are also addressed.

In considering self care deficiency and health deviation needs the respondents turned mainly to the conventional health care systems. Alternate treatments or home remedies were not the choice of the respondents. This is different from some of the published studies such as those of Kronenfeld and Wasner (1982) and Cassidy, Jabob and Bresnihan (1983) which have

shown that people tend to resort to traditional ethnic and cultural practices when they are faced with chronic illness. This could be explained by the kind of respondents, their educational level and their acceptance of mainstream health practices which are reflective of Western society in North America.

Demographic Data

Demographic data revealed that it was a relatively homogeneous group in that respondents were white, middle class, literate, had a relatively high education level with a mean of grade XI, and belonged to an arthritis self help group. Although various ethnic groups of origin were identified, the subject population was primarily European in heritage thus tending to share a similar world view. The ratio of males to females in the sample reflected the incidence of R.A. among the general male and female population. Membership in the self help group reflects self-direction as well as getting information from the self help group newsletter which was provided to all members. Many of the respondents indicated the newsletter was a source of information about R.A. and its management. Data shared by the respondents revealed that the information was mainstream; that is, it reflected the North American and Western focus on disease and its treatment. This is not necessarily a focus in all cultures and societies. In North America the myths and rituals prevalent in primitive non Western societies have been

replaced by an acceptance and faith in the biomedical model which in turn has helped to shape beliefs about the nature of disease and illness and their treatments (Hughes, 1978).

Self Care Requisites and Demands

Findings revealed the presence of self care requisites and demands, as well as deficits in self care. Individuals with inherent beliefs, values, needs, attitudes and experiences interact constantly with the environment whether for requisite attainment or to seek assistance where a deficit has been identified. Each individual faces certain demands throughout the course of the lifespan. The onset of a chronic illness often produces a disruption in life flow for an individual (Bury, 1982). Findings revealed that the impact of the chronic condition, R.A., produced a deviation in health, in structure and function for all respondents. The impact of R.A. has been well documented in the literature (Rodnan & Schumacher, 1983; Kazis, Meenan & Anderson, 1983; Panush & Yonker, 1984). Quality, if not quantity of life is often compromised by the diffuse and unpredictable nature of the R.A. associated with remissions and exacerbations. Several respondents noted difficulty in the meeting of universal needs such as rest and activity due to the pain and inflammation.

Data revealed that maintenance of a balance between solitude and social interaction was problematic for many respondents. Several expressed feelings of loneliness and isolation due to an inability to reciprocate in entertaining.

Humans are by nature gregarious. Burckhardt (1985) has noted that difficulties due to disease as well as obstacles to forming and maintaining social relations, place an extra burden on the individual.

Findings also revealed that the psychological component was also affected in the health deviation imposed by the arthritis. Several respondents expressed feelings of altered self esteem and self concept with achievement of developmental tasks made difficult. This poses an added burden on the individual for as Brillhart (1986) has noted, non acceptance of self associated with varying degrees of disability may result in feelings of low self esteem, "worthlessness, inadequacy, depression and self blame". As a compensation to the disease, a negative attitude and depression may be evident (Ehrlich, 1983).

The arthritis process affected the employment status and resulted in early retirement for several respondents. The achievement of job skills and occupational security is a developmental self care requisite (Orem, 1985). A few respondents had employers who were supportive and sympathetic. One respondent indicated self employment. Yellin, Lubeck, Holman and Epstein (1987) had considered the impact of R.A. and O.A. (osteoarthritis). Their study found that individuals with R.A. experienced losses in full or part time work as well as overtime. A study by Meenan, Yellin, Nevitt and Epstein (1981) also found major losses in the area of work, finances

and family structure. Their study also indicated that those with the most severe forms of the disease and/or disease of longer duration were also likely to be more disabled and not working. This did not necessarily hold true for the respondents in this thesis study. Several with the disease for 15 years or longer had worked to retirement. A few with juvenile onset R.A. had developed more severe forms which necessitated quitting or reducing work. Severity of disease rather than duration tended to be factors. In the study two factors, self employment and workplace autonomy, were found to have played a part in decreasing the probability of disability.

The financial situation of the respondents was not specifically explored as access to health care is not an issue in Canada. No respondent indicated that finances was a major problem in the use of the conventional system and treatments. However it emerged as a factor in considering alternate treatment modalities.

Self Care Deficits

A deficit occurs when self care agency is not sufficient to meet the demand. As Orem (1985) had noted, this may involve a limited ability to carry out measures or be a lack of effective self care. For an individual to be able to perform effective self care relevant knowledge is a necessity (Levin, 1978; Orem, 1985; Rovers, 1987).

Knowledge deficit was a self care deficit indicated by

the respondents. Initially this was reflected as not knowing what was going on in the body when symptoms first began to develop. All perceived a deficit in being able to self diagnose and sought medical assistance from the conventional health system for information and treatment. A few of the respondents had noted that on initial diagnosis they were told little or nothing about the diagnosis and its management. The time of disease onset and diagnosis is crucial for the conveying of facts about the condition and its treatment in order to allay fears and maintain hope (Rodnan & Schumacher, 1983). Many of the respondents noted that knowledge was necessary for decision making. Findings indicated that several respondents self identified as information seekers who actively sought out specific information in order to meet self care needs. Other respondents had reported themselves as being unsure of what to ask in order to clarify when uncertain. Several respondents had indicated that they perceived no other alternative to conventional, prescribed treatment for the management of R.A. This reflects, in part, a "limited ability to imagine alternate courses of action that could be taken" (Orem, 1985, p. 127.) It is limited because consequences of other actions, specifically the use of alternate treatment modalities, had been based on an insubstantial or incomplete data base concerning alternate treatments. A deficit in knowledge was revealed, then, concerning the disease itself and in varying degrees of its

treatment by both conventional and alternate means.

Findings also revealed other self care deficits or limitations for "engagement in result-achieving courses of action" (Orem, 1985, p. 127). These were perceived as a lack of resources for self care and a lack of support needed to sustain individuals in self care. As Rodnan and Schumacher (1983) have noted, a team approach consisting of variety in treatment based on individual needs assessment is important to a successful outcome. Respondents also reported a deficiency of support from others in the form of lack of empathy from family, friends or health professionals. The importance of family support has been documented by Miller (1983). The importance of family and social support as promoters of physical and psychological well being in individuals with arthritic disorders has also been addressed by Esdaile and Wilkins (1989).

The deficits to self care addressed above were noted by respondents and reflected personal factors as well as factors external to the respondents. Self care practices reported by the respondents indicated self care agency.

Self Care Agency

Agency involves the acquired ability to meet self care needs in order to promote and maintain function, development and a sense of wellbeing. The age of the respondents did not appear to have influenced agency. The youngest were not found to be the most capable of practising self care nor were the

oldest respondents found to be the least capable.

Education may have influenced self care capability. All members of the group were literate with the majority having completed secondary education. As members of the Arthritis Self Help Group, each received the newsletter on a regular basis. Many of the respondents referred to the newsletter as a source of information about R.A. and its management. As Rovers (1987) has suggested, learning, so necessary to self care, would be incomplete without the appropriate readiness which is evidenced, in part, by each respondents voluntary membership in the self help group.

Health state appears to have played a part in self care ability. All respondents reported some impact of the arthritis over time. Some had reported the disease condition as pushing them to the point of desperation. Mason, Weener, Gertman and Meenan (1983) have documented that amongst a group of chronic diseases, R.A. and pulmonary diseases produced the poorest health status on scales which measured mobility, physical activity, dexterity, household activities, activities of daily living, social activity, anxiety and depression as well as pain and general health perceptions. Similar findings in terms of personal cost related to pain, disability and limitations to physical activities were also reported by Spitz (1984).

Religious or spiritual orientation was indicated by most

respondents with some using it to cope with R.A. Studies have shown that religion plays an important component in one's perceptions of health and illness. Along with ethnicity, religion is also a determinant of an individual's interpretations of the environment and events within the environment (Spector, 1979). Age, religion, education and ethnic factors appear to have had a lesser impact on the self-care agency of the respondents. Health state has played a larger role. Collectively, the group of respondents demonstrated a wide range of behaviours indicative of self care agency rather than of deficit in self care. This may well reflect length of time with the disease which was an average of 14 years and adaptation to disease impact.

Self Care

Self Care and General Practices

Self care practices were related to the body (nutrition, exercises and movement, medications, use of health care providers) and the mind (such as use of supportive relationships, psychological coping strategies and relaxation). Pacing and prioritizing of activities and movement were identified by many as a way of coping. As Miller (1983) has noted, energy is often depleted in chronic conditions such as arthritis and efforts to conserve energy and balance its use need to be considered and used. There was consistency in adherence to prescribed conventional treatments, particularly medications (chemotherapeutics) as a means of coping.

Reliance on conventional providers and their treatments may be viewed as producing a need for and being a coping strategy. On initial diagnosis, several respondents expressed feelings of anxiety or shock which resulted in initial denial of the condition. In turn, the going to a physician, the taking of medication or using some other treatment may in itself be a coping mechanism or strategy over time as some benefit is derived from health system usage, and subsequent use decreased anxiety and uncertainty.

Consistent use of the conventional health system and treatments reflected two factors. The respondents perceived more benefit than risk from the conventional health system and there was a belief and trust in its modalities and practitioners. In an American study, Thompson (1986) considered the perception of risk and willingness to pay in the context of the impact of pain, anxiety, suffering, altered self esteem, social roles and activities on the quality of life imposed by the arthritis. Impairment of activities of daily living was strongly associated with willingness to pay while pain was associated with maximum acceptable risk. Willingness to risk also grew with disease duration which may have reflected increasing desperation. An increase in education level was related to a decline in acceptable risk. In the present study some respondents implicitly addressed a low willingness to pay for alternate modalities. A few respondents did indicate that some conventional prescribed

medications were costly but they had partial or complete coverage offered by health insurance.

In terms of risk, few respondents expressed a willingness to risk related to alternate modalities. Most respondents did not define "harm" but indicated it as a factor in determining whether to consider or not consider a modality. No respondent indicated a willingness to risk death even with conventional, prescribed treatments. This may reflect a lack of desperation, but this is not likely because several respondents noted desperation. This desperation was not related to a willingness to consider alternate modalities. One respondent had noted that desperation was a factor in feeling vulnerable and therefore contributed to a willingness to try a potentially risky conventional treatment which the physician had wished to prescribe. The respondent reported that definite benefit had been achieved thereby reinforcing the sense of satisfaction and trust in conventional practitioners and treatment.

Respondents turned to and used conventional rather than alternate system providers. This may to some extent reflect past family health practices of the family of origin. Data revealed that there was generally little use in any respondents' families of origin, of alternate system providers or modalities to deal with health and illness.

Self Care and Coping Practices

Respondents tended to display or recount more examples of

self rather than other reliant coping strategies. Self reliance was reflected in the use of comparing behaviour. Through this strategy others, either with or without arthritis, were viewed as being "worse off". This helped to reduce the negative perception and to some extent the hopelessness of one's situation. Rideout and Montemuro (1985) defined hope as "an expectation greater than zero of achieving a goal. It is characterized by the belief that there is a way out and that with help the individual can manage changes in his being" (p.429). In Rideout and Montemuro's study involving individuals with chronic heart failure, hope, along with morale was found to be a significant variable in social function, reflecting involvement in life. This reflects in part the coping strategies of perceiving and using support and having other interests and activities. Most respondents perceived that they had supports available and that support had been offered. Respondents reported that it had been received from family, friends, employers, co-workers and, to some extent, was identified as received from health professionals. The role and importance of family support was addressed by Ferguson and Bole (1979) who noted that patient compliance was blocked by family members who interfered. Interference by family members was not reported by any of the respondents. However, family support was an important factor for many respondents. Miller (1983) had noted that family support helps to "maintain psychological stamina as a power

resource" for people coping with chronic conditions.

Keeping busy, having distractions, motivations and other interests were also reported as coping strategies by half of the respondents. This involved not focusing on the self and physical symptoms. Rather, through assuming of roles and socialization with others, as well having other interests, distractions and motivations, the individual could maintain a functional self and personal integrity. Miller (1983) has noted chronic illness enhances feelings of worthlessness and being "different". Having accomplishments, helping others and generally keeping busy were identified as ways of not focusing on the arthritis, but rather the self as a whole person. Being able to achieve, accomplish and rise to challenges was cited by almost half the subjects as being important means to enhance feeling worthwhile, "useful" and of raising self esteem. Support for purposeful activity as an "energizing effect" to help cope with chronic conditions has also been reported (Kincheloe, 1979).

Acceptance of self and modification of attitude or perspective were reported by a majority of the respondents. Self acceptance is an essential factor for those with disabilities. This entails a realistic but positive acceptance of the self and the chronic condition and to getting on with living and coping with the disability. The self accepting person with some disabling limitation tends to rely on internal rather than external values to guide

behaviour, has faith in personal ability, accepts responsibility for own behaviour, accepts feelings, abilities and disabilities, sees self worth and does not see the self as totally different from others (Brillhart, 1986). Several respondents stated that they were more than just "crippled hands" indicating that they had accepted the chronic condition. Some displayed healthy acceptance of dependence on assistive devices.

Many respondents had indicated a change or refocusing of perspective or attitude in order to achieve their current position of psychological and, at times, physical comfort with the arthritis. While the majority had indicated a change in attitude or perspective, some of them also indicated evidence of possible nonacceptance by reporting feelings of inadequacy, past depression and self-blame. This is not surprising when one considers the potential impact of arthritis on so many different realms of an individual's life. Chronicity bears with it not only the burden of specific problems but also the knowledge that recovery is not complete. As a companion to this is the notion that there are social expectations associated with being ill and assuming "patient" roles, and also for giving up those roles and resuming "pre-patient" role and activities (Spector, 1979). This is an appropriate perspective when the condition is acute, but with chronic diseases recovery is not the end result. Consequently, ongoing adjustments in attitude and lifestyle must be made

when faced with a chronic condition such as arthritis.

Information seeking or information use as a basis for decision making was identified by a majority of respondents as another coping strategy. The importance of having a knowledge base for self care management and for decision making was stressed. The importance of patient education to adherence to prescribed regimens and to effective self care has been noted by others (Levin, 1978; Miller, 1983; Rovers, 1987). For some respondents it was enough to seek information and resources on their own. For others it needed to come from the physician specifically, as a credible source. As Berger (1969) suggests, this reflects the seeking of plausibility of knowledge through a form of social interaction. Most blended both approaches with more of a reliance on conventional health system practitioners, such as physicians, physiotherapists and to a lesser extent, nurses as a source. Although professionals were the primary source of information pertinent to self care management, the perception of the education process and experiences was not always a positive or satisfying one.

Self Care and Health Care Professionals

One of the main roles of health professionals is to facilitate the self care agency of the individual in order to have effective self care, thereby restoring or maintaining the integrity of structure and function (Levin, 1978; Miller, 1983; Orem, 1985; Rovers, 1987). This is achieved through use

of the supportive educative system (Orem, 1985). One way of facilitating agency is to promote factors which increase the individual's or family's self care agency. Some of the deficiencies in the health care system concerning this were identified by several respondents as a lack of programs offering counselling to individuals regarding the "mental problems" associate with arthritis, or counselling for families as how to cope with the affect as a unit and to be able to offer support for the affected individual. Development of personal, self reliant coping strategies such as increased assertiveness could be stressed. Several respondents identified benefit achieved from participating in a Wellness Program which resulted in increased assertiveness in communicating with health professionals and others. From the respondents' comments it appeared that the supportive component is a crucial one in the health provider-consumer system as it relates to the management of arthritis.

Establishment of a supportive relationship is based on an effective interpersonal relationship between health professionals and consumers of health care. Communication and affective components are vital factors in an interactive process. This applies equally to all professionals. Very few respondents reported having had contact with a nurse in the community. Most respondents had been hospitalized and had interacted with nurses in that setting. Surprisingly, nurses were mentioned very little by the respondents as supportive

health professionals. Favourable comments were generally non expansive. Negative comments about nurses tended to be more expanded and focused on the nonsupportive behaviour. This was indicated as a poor knowledge base concerning arthritis resulting in a lack of empathy and sensitivity toward the suffering of the individual and toward the knowledge which the individual had derived from personal experience. Rovers (1987) has suggested that nurses need content expertise to provide effective counselling to patients. Other comments from the respondents indicated a desire of nurses to control the situation. This may reflect paternalistic practices of nurses who have been socialized into the subculture of the health profession. Fromer (1981) has suggested that nurses, who are essentially powerless in the health system, "bolster their own autonomy and authority by restricting the liberty of those lower down" (p.287). It may also reflect the context of chronicity in which "the burden of living with the disease and achieving the best control of the disease is on the patient himself" (George, 1984, p.14). The focus of care should enable the individual to gain greater control over the condition.

Respondents offered more comments about physicians and the relationships with them. Remarks indicated both positive and negative experiences and perceptions. The importance of the relationship with health professionals and its influence on patients has been addressed in several other studies

(Jette, 1982; Falvo & Achalu, 1983; Cameron & Gregor, 1987). Jette (1982) has noted that the patient-provider relationship is often disappointing to both and results in low levels of patient cooperation with professional recommendations. Cameron and Gregor (1987) have noted that "arthritic patients who described their physician as 'personal' were more likely to adhere to recommended treatments" (p.673). Several respondents spoke of the caring and support received from their physicians in terms of empathetic responses but also in terms of the time taken to allow for questions and venting of fears and anxieties.

Communication which allowed open expression of concerns was found to be effective and resulted in satisfaction for many respondents. A few cited the use of "jargon" as resulting in limited comprehension of the intended message. Use of simple, clear, appropriate language is critical in order to not confuse the issue further. Hodson (1967) has noted that the success of the therapy is dependent on the ability of doctor and patient to understand each other. In considering factors which led to patient "involuntary noncooperation" Jette (1982) suggested that knowledge of communication process and skill in patient were necessary.

Effective communication is necessary for the educative process. Accurate information improves cooperation. Furthermore, information dissemination should be tailored to the individual needs. Several respondents noted that no

information about arthritis or its treatment was offered by the physician. Others indicated there was so much of it that it was overwhelming. Some acknowledged they had a knowledge deficit, but did not know what to ask or were too intimidated to ask. Individuals turn to health professionals when a need arises and with which they need assistance. This seeking is predicated on the trust that individual needs and goals will be met (Lynch, 1976). In order for the goals to be met the individual must know and understand the recommendations or noncompliance, or involuntary noncooperation might be the result (Jette, 1982). Physicians tend to overestimate patient cooperation and this might be due to insufficient knowledge about the individual's own health care practices concerning the disease and its management. Taking time to question the individual and seek pertinent information about self care activities also could suggest empathy and sensitivity to individual's rights. It is a way of forging rapport with and confidence in the physician without which individuals might turn to other persons or modalities for help if they believe that help is possible (Rovers, 1987).

Educating the individual in order to promote effective self care also entails recognizing or at least assessing the learning style and being aware of factors affecting learning. Some respondents indicated they were information seekers and found resources on their own with little or no assistance from professionals. Others indicated they did not know what to ask

while others indicated some knowledge had been sought out, but physicians did not always supplement it effectively. A few indicated pamphlets or the like had been supplied as support resources. Lynch (1986) noted, that ongoing education is necessary to reinforce information and combat ignorance of facts which may in turn aggravate anxieties.

The setting may also prove to be a factor, as several respondents noted that the group environment and format of the self help group were both informative and supportive. The self help group also helped to serve a reinforcing function for information initially conveyed by professionals. Physicians, nurses, physiotherapists and other health professionals participated as guest speakers at self help group meetings. Written information was supplied in part by the Arthritis Society. Through involvement with the self help group, reinforcement of the use of conventional treatment resulted. While the focus of the thesis was not epistemology, an awareness of epistemological argument is acknowledged. Individuals learn about the world and themselves in a social context. When a group of people hold the same world view and in this case an acceptance of the positivist/scientific world view it may be considered to be a "cognitive" majority (Berger, 1969, p.7). This world view is further validated by those held up as authority. Those who do not share the same scientific world view and who may support the supernatural or nonempirical as a "meaningful reality" are considered to be a

"cognitive minority" (Berger, p.7). The role and value of self help groups have been addressed by others (Corbin, 1983). The self help group, then creates a cognitive majority forum which supports the epistemology of the medical establishment and as such depreciates the value of non-orthodox systems. Those who align with this group would be expected to be only minimally, if at all, participants in alternate modes of healing. The study's data clearly supports this hypothesis.

Some references were made by respondents of having been in specific information sessions such as physiotherapy classes for particular exercises. Some studies have indicated that the group teaching format does not appeal to all (Rovers, 1987). Not noted, but worth mentioning is that self help groups do not appeal to all. Respondents gave no indication as to liking or disliking the format, although a few noted they found guest speakers "interesting" or beneficial.

The mere giving of information does not guarantee change in behaviour or an adherence to the regimen associated with that information (Levin, 1978; Cohen, Sauter, Van Houton, De Vellis, R. & De Vellis, B., 1986; Rovers, 1987). There also needs to be a belief in the value of the information as well as the participation of the individual, to some extent, in the decision making concerning the treatment. Health and illness need to be seen from the individual's perspective (Ruffing-Rahal, 1985). Values and beliefs of both the individual and professional need to be considered, for each has had different

enculturating experiences. There is a belief within the conventional health system of the omnipotence of technology (Spector, 1979). Many of the respondents indicated some awareness with their perception of benefit derived from surgery and anticipated future surgeries. Not all cultures rely on technology or turn to it (Falvo & Achalu, 1983). Indeed not all health professionals subscribe to the same beliefs as is evidenced by a rise in the number of physicians practising holistic medicine (Goldstein, Jaffe, Sutherland & Wilson, 1987). Individual professional practitioners such as nurses and physicians should be aware of their value bases and beliefs. This is particularly important when issues of control and decision making are considered. As Trandel-Korenchuk (1982) has noted the individual has a right to self determination. This is a vital point to remember when considering self care. The overall goal of self care education is to foster awareness, influence attitudes and identify alternatives, but always with the individual's perspective and goals in mind (Levin, 1979; Rovers 1987).

Levin suggested patient teaching is actually geared toward achieving system goals rather than the individual's and gives the primary control to the caregiver. He further suggests that teaching should be directed at self care education in order to foster "autonomous healing capabilities". In order to achieve this Stern and Harris (1986) suggest that "cultural elasticity" must be in place to

allow for a greater congruity and not incongruity between the perception and valuing of self care by the caregiver and the individual.

According to Trandel-Korenchuk, (1982) there are three possible models of decision making for use between professionals and consumers of health. Active passivity has the greatest control by professionals. Guidance - cooperation is perhaps seen most frequently with the caregiver sharing selected information and has a paternalistic tone. The ideal is mutual participation with each seen as equals in the relationship. The preferences of individuals for control and degree of participation in decision making must be considered (Trandel-Korenchuk, 1982; Dennis, 1987). Comments by some respondents indicated they had participated in a guidance-cooperation model with information and the guidance of the physician sought prior to decision making. Some expressed total trust in the physician and did not question decisions. A few indicated preference in decision making and some control over their planned care. These individuals had a tendency to identify the awareness of self responsibility. All of the respondents indicated a belief in the conventional health care system and its providers and a trust in physicians in particular.

Limitations of the Study

The findings of the study must be considered within the context of its limitations. Internal validity was threatened

by the possibility of the researcher affecting the responses of respondents and by the researcher imposing personal perceptions on the findings which emerged from interview data.

Efforts were made to safeguard against threatening internal validity. Some degree of rapport and comfort was achieved between the researcher and each individual being interviewed. This was accomplished through initial phone contact, time for questions during the interviews and researcher sensitivity to respondents' reactions. Thus differing levels of comfort and trust may have been achieved with each respondent interview. At no time did the researcher get the impression that information was being deliberately withheld.

Internal validity may have been compromised in not meeting with each respondent at least one more time in order for respondents to review the tentative categories of coding which had emerged. This was due to time constraints. This problem was anticipated during the interviews and as a category seemed to be emerging clearly from the data, possible codes were reflected back to the respondents. This produced some success during the interviews.

The research was conducted when each respondent had experienced the arthritis for a period of time ranging from five to thirty-one years. The retrospective nature of this study may thus further threaten internal validity. Some respondents acknowledged they were having difficulty recalling

events and their timing accurately. Each respondent had also experienced the arthritis condition very differently over the course of time with some distortion possibly being injected into the recollections. All respondents also had reported meeting with varying degrees of success with treatments tried and the degree of satisfaction or dissatisfaction may also have affected recollections. Nevertheless, each respondent was able to share various perceptions of his/her experience with the arthritis and its management through the health care system and self care management.

Efforts were made to reduce the threats to external validity. Several transcribed interviews were read by two nurses with Master of Nursing degrees, working in the field. There would have been value in offering transcripts for consideration to other allied professionals in the field with graduate degrees, such as physiotherapists. Coding was also started many months after the interviews were conducted. While there is value in detaching from the experience in order to bring greater objectivity to the task, there is the danger of being too removed and not recalling other contextual stimuli from the interview period. This was offset, in part, through the use of a journal used to record impressions of the interviews shortly after they were conducted. Also, the researcher herself had done all the interviews and had transcribed the majority of the interviews thereby reinforcing the recollections of the interview experience.

The sample selected reduces external validity of the findings. While the sample size is sufficient for a qualitative study of this nature, bias was possibly introduced in selecting the sample from a specific group, the Arthritis Self Help Group. This group appears to have shared a similar perspective of arthritis, its treatment and overall management. All respondents volunteered for this study, and it is assumed that they did so because they had perceptions which they wished to share. While respondents shared some similar experiences related to the arthritis condition and membership in the self help group, each also brought a rich repository of very personal and unique experiences from a time before membership in the self help group. Nevertheless, it is acknowledged that although each has individual perceptions, the perceptions expressed by the respondents also reflect a possible group perspective which in itself may be viewed as worthwhile.

While interesting findings emerged, it is not possible to generalize these findings to all individuals with arthritis or even to all individuals with arthritis who are members of a self help group. While some homogeneity was evident in the sample, the data reflect perceptions of unique individuals with varying experiences. The findings from this study present various perceptions that the respondents had concerning efficacy and use of both the conventional and alternate health systems. An intent of the study was to

generate findings which might help health care workers to see a broader range or perspective of those living with a specific chronic condition.

Implications of the Study

The findings of this study suggest implications for nursing as well as other groups of health care providers. For nursing, its practice, education and research are implicated in the findings. Respondents noted physicians and physiotherapists most frequently in their comments with nurses, social workers, occupational therapists and nutritionists noted less frequently.

The majority of respondents had been hospitalized and therefore would have encountered nurses but there was a slight tendency for respondents not to name them unless a particularly positive or negative (satisfying or dissatisfying) situation or event was being recalled. Otherwise, nurses were noted as being "nice", or "very good". Nurses, as frontline providers of care, need to be more visible to the individual and families with whom they are working. If effective self care, through patient education is a goal of nursing, then nurses need to work collaboratively with clients/patients to achieve this. Nurses, as well as physicians and physiotherapists need to be seen as active, contributing and integral members of the health team. Nurses need to be aware of and feel comfortable as partners in the health team. They need to be able to convey assessments and

concerns about clients to other health team members and to clients and their families.

Nurses, in any clinical setting, need to be aware of the importance of information in self care and their role in disseminating that information. Not only the client/patient, but also the family often needs information. In order to be able to convey that information, the nurse must have a solid knowledge base. This knowledge base needs to be based on current research, not only in nursing, but other related fields as well. In providing necessary knowledge to individuals and their families, nurses need to recognize that each individual has different needs and different styles and preferences for learning. A question, simply put is often sufficient to determine the need for specific information. Expectations of patients/clients concerning information dissemination would also need to be determined. It may be an expectation that as health care providers, nurses or others, offer the information without being asked to do so.

In light of the impact and the burden which a chronic disease, such as Rheumatoid Arthritis can place, nurses and other health professionals need to be aware of the affective domain in assessing and interacting with the individual and family. Suffering may not always be visible. Sensitivity to another's feelings and the ability to convey sympathy or empathy are critical to a caring profession. Nurses and other health providers who were able to recognize that an individual

was suffering, had feelings and had a right to individual expectations and perceptions were perceived by the respondents in this study as being supportive. Health care providers also need to be cognizant of the part that emotions, both positive and negative, can play at various stages in a chronic condition in enhancing, but more particularly, in blocking understanding of a diagnosis or prescribed treatment. Taking time to explain or to come back and report previous information may make the difference in an individual feeling more comfortable in the chronic condition.

Nurses and others need to be aware of the importance of the family in individual well-being. Families often support, but in times of stress have their own needs. Nurses need to have knowledge of family structure and function and the role members have. Consideration of the family and its needs must be an integral and major component of the health team's plan of care for the individual.

Findings also suggested implications for nursing education. Chronicity has been identified as a growing health care problem. A sound knowledge base of chronic conditions is vital. When one considers the multiple toll inflicted on individuals and families by arthritis, inclusion and emphasis of it and other such potentially disabling chronic conditions in any nursing programs curriculum is essential. Finally, nurses need to be aware of the right of individuals to make choices based on relevant information. The profession of

nursing, and other professions within the health care system, consist of a subculture with values, beliefs, assumptions and practices which may be quite different from those of the individual. As self care often takes place in a community setting, self care practice and preferences of individuals need to be considered in planning care. While values and chosen self care practice may often be congruous with those of the health care providers, recognition must be given to the instances when incongruity occurs.

Recommendations

Implications for nursing research are discussed in light of recommendations for possible future research. Because of an identified dearth of studies existing which addressed the individuals' perceptions of alternate modalities, the study was initiated using an exploratory, factor isolating level of inquiry. Based on the findings which emerged and consideration of limitations, recommendations for further nursing research are offered.

There is a need to explore the experience and perceptions of adult individuals with R.A. who do not necessarily belong to a self help group and who function within the community. These individuals might well have different perceptions from those expressed within a self help group context. In order to determine how perceptions change with experiences and increased exposure to information, a longitudinal follow-up study could be conducted. A sample of newly diagnosed

individuals with R.A. could have perceptions and knowledge level tested pre and post intervention by health care professionals. Perception of feelings and use of coping strategies as the individual faces the challenge of the chronic condition could provide valuable data for assisting others who are newly diagnosed.

Because of the findings which suggested a deficit of knowledge among nurses and physicians concerning arthritis, further research needs to be done to determine the knowledge level of nurses in this area and their overall attitude to chronic conditions and to R.A. and its management by a variety of means. Individuals tend to be motivated to learn when there is interest in an area. The perceptions of family members concerning the disease, its progress, treatment and affect on the individual could be explored. The family has been identified as an important area of support. For this support to be most effective, it needs to be based on correct information rather than misconception.

Finally, physicians were identified most frequently as a key source of information. The role and physicians' perceptions of their own role needs to be explored. Physicians, and other health professionals to an extent, are gatekeepers of information and of access to components of the health system. In arthritis, or any chronic condition it is important that the physician and individual work together to promote self care. If incompatibility exists with regard to

values, practices, control and decision making, effective self care may not occur.

This exploratory study has yielded data which attest to the complexity of living with a chronic condition. Further research in this area will help to broaden the knowledge base of perceptions concerning health systems and various treatment modalities in the management of R.A.

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Appendix A

RESEARCH QUESTIONS

1. What knowledge, whether medical or popular, does the individual have regarding the disease and its treatment?
2. What degree or level of satisfaction/dissatisfaction is expressed with prescribed, conventional treatment?
3. What prescribed and/or unprescribed modalities do arthritics use to manage their diseases?
4. What knowledge, medical or popular, does the individual have regarding alternate treatment modalities?
5. What was the source of information regarding prescribed and alternate treatment modalities?
6. What information about alternate modalities is provided in the patient teaching offered by the health care system?
7. What value is given to alternate treatment modalities?
8. What value is given to a combination of prescribed and alternate modalities (complementary/adjunct therapy)?
9. What experience with arthritis prompted consideration and/or use of alternate modalities?
10. What was the effect of any alternate modality used?
11. What information about alternate modalities is shared by individuals with arthritis?
12. What role do self help groups play in the perception and possible use of alternate modalities?

13. What role do demographic characteristics play (ie. age, gender, length of time with disease, education level, employment and marital status, religion, and ethnicity) play in the formation of perceptions about alternate modalities?

Appendix B

LETTER OF ACCESS TO THE BOARD OF DIRECTORS

Board of Directors/Executive Committee,
The Arthritis Society Self-Help Group,
825 Sherbrook Street,
Winnipeg, Manitoba.

Subject: Research Project.

I am a student in the Graduate Program, School of Nursing, University of Manitoba. I am in my second year and am ready to commence my research project for my thesis requirement. My thesis is being supervised by Dr. Theresa George.

My area of interest is chronic disease, more specifically Rheumatoid Arthritis in the adult. My chosen thesis topic involves an exploration of the adult arthritic's perception of the efficacy and possible use of alternate (unprescribed) treatment modalities in the self-care and management of Rheumatoid Arthritis. These alternate treatment modalities (A.T.M.) may be considered to be anything other than the prescribed, conventional treatment.

I would like to obtain the participants for my study through contact with the Arthritis Self-Help Group. Upon receiving approval from the Ethical Review Committee of the School of Nursing, University of Manitoba, I would like to approach the membership at a general meeting. The purpose of the study would be explained. Ethical considerations concerning consent, confidentiality, anonymity and the right to withdraw at any time would be addressed. It would be

stressed that participation is voluntary. I would like to be able to approach the membership at the April general meeting.

Subject participation would consist of a taped interview lasting a minimum of one hour and a maximum of two hours. The taped material would be coded to assure anonymity. The time of the interview would be arranged to suit participant convenience. A minimum of ten and a maximum of twenty subjects is sought for the study.

I would be happy to attend a Board meeting in order to explain my study in person and to answer any questions that you might have. I look forward to further discussions with you.

Sincerely

Diana Pallen

Appendix C

INTRODUCTION TO POTENTIAL SUBJECTS

Hello. My name is Diana Pallen. I am a nurse with several years of experience in caring for individuals with a chronic illness. Many of these patients have had some form of arthritis.

I am currently a Masters student in the School of Nursing, University of Manitoba. To fulfil my thesis requirement, I would like to conduct a research study in the area of Rheumatoid Arthritis and how adults with the condition experience and manage it. My thesis supervisor is Dr. Theresa George.

Would you be interested in hearing about or reading the explanation of the study? You do not have to decide whether to participate until you have had more time to consider the explanation of the proposed study. I wish to stress that your name will not be revealed and any information that you give to me would be kept confidential. Are there any immediate questions? You may explain the study to your family or to others significant to you. I have included my name, telephone number and address on the Explanation of the Study form. Should you have any questions or decide to participate, please contact me at the number provided. Copies of the forms addressing consent and study explanations will be left with a member of the Executive. If you are interested in participating, please give me your name and telephone number.

Thank you for your time and attention.

Diana Pallen (R.N.)
Masters Candidate

Appendix D

NEWSLETTER INSERT

I am a nurse in the Graduate Program in Nursing at the University of Manitoba. I am interested in people who have Rheumatoid Arthritis and how they manage their arthritis. As a requirement for my de4gree, I am doing a study to find out how people with arthritis manage their condition. As a nurse, I have taken care of people with Rheumatoid Arthritis. Upon completing my degree, I hope to continue to care for those with arthritis. This study will hlp me to better understand the needs of individuals with arthritis.

I am looking for volunteers. If you are willing to participate in this study, please contact _____ (Executive Committee Member).

Appendix E

FOLLOW-UP TELEPHONE CALL

Good morning/afternoon/evening. My name is Diana Pallen. I am a Graduate student interested in doing a research project involving adults with R.A. I believe that you have indicated an interest in this study. Are there any questions you might have that I could answer to help you decide whether to commit yourself to this project? May I meet with you sometime to explain what the study is about? (At that meeting, the purpose, method of data collection, consent, confidentiality and anonymity would be reviewed).

I would like to set up a time for the interview that is convenient for you. When would it be best for you? May I just confirm the spelling of your name and address? Thank you for agreeing to participate. I look forward to seeing you on the _____ at _____ hours.

Name _____ Address _____
Telephone _____

Appendix F

EXPLANATION OF THE STUDY

As an adult with rheumatoid arthritis, you are invited to participate in this study. Its purpose is to ask you to talk about the experiences you have had in living with and managing your arthritis.

This study is being conducted by myself, Diana Pallen, a nurse who is a Masters student in the School of Nursing, University of Manitoba. The advisor for my study is Dr. Theresa George. You do not have to participate. If you decide not to, it will not affect any care or services available to you.

If you do agree to participate, you and I (D. Pallen) will decide on a suitable date and time for the interview, which would last one to two hours. It can be done in two sessions if necessary. The interview will be held in a place comfortable for you. The session will be taped using a recorder. You will be asked several questions about your arthritis and what treatments (prescribed or not prescribed) have been used to manage it. Your beliefs and actions are not being judged.

If you decide to participate, you can withdraw at any time. Information you give, will be kept confidential. Your identity will remain anonymous.

To find out whether you will be able to participate in the study please consider the following:

1. Are you between the ages of 20 and 65 years?
2. Was your diagnosis of Rheumatoid Arthritis made by a physician?
3. Have you received teaching/education about rheumatoid arthritis and its treatment from a health care provider?
4. You are currently not in the hospital nor due to go into the hospital during the eight weeks of the study.
5. Do you live within the Winnipeg city limits?
6. Do you have a telephone?

If you can answer "yes" to the above questions, you are eligible to participate in the study.

I, Diana Pallen may be reached at telephone number 269-6765.

Appendix G

CONSENT FORM

This certifies that I, _____, having met the conditions, agree to participate in the research study, conducted by Diana Pallen, Reg.N., a Masters student in Nursing at the University of Manitoba. It is being supervised by Dr. Theresa George. I have been given a copy of the written explanation of the study and have had a chance to ask questions. I understand that my participation involves having an interview in a setting and at a time convenient to myself. I am aware that the interview will last one to two hours. If more time is needed, the interview may be done in two phases. I understand that if I get tired or uncomfortable, the interview may be stopped and continued at a later date. I am aware that I will be asked questions about my experience with Rheumatoid Arthritis and treatments that I believe can be used to help manage the disease. I understand that I do not have to answer any questions that make me feel uncomfortable. I may refuse to tape part of the interview. I am aware that I am participating voluntarily and that I am free to withdraw at any time. I understand that the study will not have a direct benefit to me.

I give permission to Diana Pallen to gather information during my participation in this study. I have been informed that the tapes will be erased at the conclusion of the study. I have also been assured that I will not be identifiable from

the study. I understand that information I give will be kept confidential between myself and the interviewer.

I understand that I may ask Diana Pallen further questions at any time. I have received a copy of the consent form and Explanation of the study, which contains the inclusion criteria. My signature below indicates willingness to participate.

(Date) (Participant) (Investigator)

I would like a copy of the results _____

Yes _____ No _____

Appendix H

INTERVIEW GUIDE

Demographic Aspects

1. Sex Male _____, Female _____ .
2. What is your year of birth?
3. What is your religion? Do you consider yourself weakly _____, moderately _____, or strongly _____ religious?
4. What is your ethnic/cultural background?
5. Do you speak any other languages besides English?
6. What is your marital status?
7. How many are in your family?
8. Do you have family members who have had Rheumatoid Arthritis? How are these individuals related to you?
9. What is the highest education level you have achieved?
10. What is your current employment status?
11. How long have you had the disease?

Knowledge, perceptions, awareness and practices related to R.A. and prescribed treatment:

1. How would you describe the disease R.A.? Could you tell me what your experience with R.A. has been?
2. What treatments have been specifically prescribed for you by your physician to manage the arthritis?
3. What has this prescribed treatment meant to you and your experience with R.A.?

4. What was your source of knowledge about R.A. and the medical treatment for it?

Knowledge, perceptions, awareness and practices related to unprescribed/alternate treatment modalities:

1. What comes to mind when you think of treatments or remedies for R.A. that have not been prescribed by a physician? How would you refer to these other treatments or remedies?
2. What usefulness or effect do you believe that these unprescribed remedies or methods have on arthritis?
3. What has been your experience with any of these remedies?
4. What was your source of knowledge about unprescribed treatment methods used to manage or deal with arthritis? When did you acquire it? Have you tried unprescribed treatment methods for any other conditions or reasons?

Miscellaneous:

1. What would be an effective treatment or combination of treatments for the management of your arthritis?
2. What role did you play or would you like to play in determining the treatment prescribed for you?
3. What would you do to make your disease more "liveable"?
4. What do you feel will give you control or greater control over your R.A.?
5. How long have you been in the self-help group?
6. Do you know anyone who has dropped out and why they did?

7. How long have you been using alternate and prescribed treatment modalities?

Appendix I
SOCIO-DEMOGRAPHIC DATA

TABLE

| <u>VARIABLE</u> | <u>Number</u> |
|--------------------------------|---------------|
| Gender | |
| Male | 4 |
| Female | 13 |
| Age | |
| Range (20-29) | 1 |
| (30-35) | 2 |
| (36-39) | 0 |
| (40-44) | 2 |
| (45-49) | 2 |
| (50-54) | 2 |
| (55-59) | 2 |
| (60-64) | 2 |
| (65-70) | 2 |
| (71-74) | 2 |
| Mean (X) age was 52 years | |
| Marital Status | |
| Single | 2 |
| Married | 11 |
| Divorced | 1 |
| Widowed | 3 |
| Education Level | |
| Elementary School Completed | 1 |
| Secondary School in part | 6 |
| *Secondary School Completed | 5* |
| University in part | 1 |
| University Completed (Bacc) | 4 |
| *Secondary School & Vocational | 3* |

| | |
|--|-----|
| Employment Status | |
| Full time | 1 |
| Part-time | 0 |
| Self employed | 1 |
| *Retired | 10* |
| *Retired due to R.A. | 7* |
| *Unemployed | 3* |
| *Unemployed due to R.A. | 2* |
| Housewife | 1 |
| Cultural/Ethnic Background | |
| Anglo Saxon (Scottish, English Irish) | 10 |
| **Polish/Ukrainian | 2 |
| Italian | 1 |
| Germanic | 2 |
| **French | 2 |
| Language Spoken | |
| English only | 15 |
| English and another language | 2 |
| Religious Affiliation | |
| Protestant | 12 |
| R.C./U.K. | 4 |
| Non-Denominational | 1 |
| Faith/Spirituality | |
| Weak | 4 |
| Moderate | 10 |
| Strong | 2 |
| Declined to respond | 1 |
| Time Since Diagnosis with R.A. (years) | |
| 1 - 5 | 2 |
| 6 - 10 | 5 |
| 11 - 15 | 2 |
| 16 - 20 | 5 |
| 21 - 25 | 2 |
| 26 - 30 | 0 |
| 31 - 35 | 1 |
| Mean (X) length of time with R.A. was 14.7 years | |
| Other family members diagnosed with R.A. | |
| Yes | 9 |
| Possible | 3 |
| No | 5 |

Membership in Self Help Group (years)

| | |
|-----------|---|
| 1 - 5 | 7 |
| 6 - 10 | 7 |
| Uncertain | 3 |

*(Some responses are indicated in more than one category)

** (Also indicated other nationalities were in background)