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Assessing Quality of Life Needs in Individuals with Juvenile Idiopathic Arthritis
and the Potential Role of Occupational Therapy

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Abstract

The trend in occupational therapy is to move toward holistic care that considers the client's quality of life. However, current practice for individuals with juvenile idiopathic arthritis (JIA) focuses on managing joint pain and degeneration and tends not to address overall life satisfaction. The purpose of this research is to 1) analyze the quality of life of individuals with JIA and related conditions, 2) identify quality of life needs and strengths in this population and 3) discuss identified needs in light of the potential role of occupational therapy. In this quantitative study, adults with JIA and similar conditions completed the shortened version of the World Health Organization's Quality of Life assessment (WHOQOL-BREF), a survey tool that measures life satisfaction. The results were analyzed in the domains of physical health, social relationships, psychological health, and the environment. This has implications in understanding how JIA and related conditions influence quality of life. Occupational therapy may be able to improve the areas in which individuals reported decreased satisfaction by providing tools and strategies that can be utilized in everyday life.

Introduction

Juvenile Idiopathic Arthritis

Juvenile idiopathic arthritis (JIA) is an autoimmune disorder that manifests in an individual before they are sixteen years of age. This type of arthritis differs from the more commonly known osteoarthritis in that it does not result from joint wear and tear, but instead stems from an overactive immune system which has difficulty differentiating between foreign substances and its body's own tissues. As a result, the immune system attacks its own joints, leading to joint degeneration if not managed effectively. It is a lifelong condition which often includes a series of exacerbations and remissions for variable lengths of time (Cakmak & Bolukbas, 2005). The manifestations of this disease include fatigue, joint pain, joint inflammation, and decreased range of motion and it can result in joint breakdown and deformity if not properly controlled through treatment (Karlsson et al. 2006).

High pain levels resulting from JIA have a variety of implications. Coping with life becomes more effortful and psychological well-being, in addition to physical function, suffers when an individual has high levels of pain. Also associated with increased pain is fatigue, which differs from normal, everyday feelings of tiredness. Chronic fatigue is not simply solved with rest and can influence one's ability to complete daily activities (Reinseth et al., 2011).

While this disorder was previously referred to as juvenile rheumatoid arthritis (JRA), the name was changed to juvenile idiopathic arthritis to reflect the unknown etiology of the condition (Dannecker & Quartier, 2009). Despite researchers being unsure of the specific cause, there have been some demographic trends related to JIA that have been discovered. As with

many autoimmune disorders, JIA is more common in women than in men. In fact, it is three times as prevalent in women (Firth, 2011). Individuals can be diagnosed with JIA as young as one year old, but the diagnostic incidence increases steeply with age until the age of sixteen (Dannecker & Quartier, 2009).

According to medical doctors Cakmak and Bolukbas from the Department of Physical Medicine and Rehabilitation at Istanbul University, there are five diagnostic criteria for juvenile idiopathic arthritis (2005). These include disorder onset before sixteen years of age, persistence of symptoms for six weeks or longer, exclusion of other types of juvenile arthritis, manifestations that fit into a sub-category of JIA, and arthritis in at least one joint or the presence of at least two of the following symptoms: (1) range of motion limitations, (2) feelings of pain or tenderness with movement of the affected joint, (3) high fever. The subcategories of JIA are determined by the number of affected joints. It is referred to as polyarthritis if inflammation is present in five or more joints and as oligoarthritis if there is inflammation in fewer than five joints (Cakmak & Bolukbas, 2005).

It has been estimated that the prevalence of childhood arthritis in the United States, including JIA and other similar conditions, was about 150 out of 100,000 as of 2008 (Helmick et al., 2008). Because this is a lifelong condition, JIA affects not only children, but adults as well. It is the most common form of inflammatory arthritis, which is the leading cause of physical disability in the non-institutionalized adult population (Cranitch, 2003). While it can result in physical disability, JIA can also cause difficulties with occupational performance across all domains (Codd et al., 2010). Those with this disorder often need to put forth greater effort not only physically, but also cognitively and behaviorally in order to carry out their daily roles and

routines. Additionally, being threatened with an unpredictable disease like JIA can have heavy psychosocial implications on an individual (Karlsson et al., 2006).

Quality of Life

Quality of life is typically measured through self-reporting scales and indicates how satisfied one is with both the positive and negative aspects of their life, including the physical, psychological, social, and environmental domains (WHO, 1996). It has been found that with those who have rheumatic diseases, indicators of better quality of life include being pain free, having good sleep routines, feeling rested after sleep, performing low effort exercise more than twice weekly, being strongly coherent, having emotional support, and having a high work capacity (Arvidsson et al., 2011).

With these factors in mind, living with JIA has been shown to have a negative impact on areas including the person's social life, hobbies, everyday tasks, relationships, and moods and emotions (Firth, 2011). Individuals with this disorder have also reported lower satisfaction with their self-care, work, and sex life than those who do not have JIA. More specifically, at the time of disease onset, only half of individuals were satisfied with life as a whole and less than half were satisfied with their leisure and work-related occupations (Karlsson et al., 2006). Because of this, those with JIA are thought to have a lower quality of life overall.

Having a condition that causes both pain and fatigue for the individual can result in a decrease in general activity level which then influences that person's participation in occupation. If the person is experiencing low levels of energy and pain or discomfort with joint movement, they may engage in fewer occupations. For example, adults with JIA perceive that pain and fatigue limit their sexual activity (Packham & Hall, 2002). It was also found that children with

JIA have less active play than do their typically developing peers (Cakmak & Bolukbas, 2005). Another area of occupation limited by this disorder is work. This can relate to performance that does not meet the employer's expectations or one's self-perception of how well they are able to fulfill their role as a worker. Unfortunately, one third of adults with this condition leave work prematurely due to the work-related difficulties that arise (Codd et al., 2010). Having JIA can also impact an individual's performance in leisure occupations. In fact, about two thirds of those with this condition have given up a leisure activity altogether (Wikstrom et al., 2001).

A person's social relationships may also suffer following a JIA diagnosis. In addition to lower activity levels that may impact a person's social participation, individuals with JIA sometimes have difficulty conveying the serious nature of their condition. Because it is an "invisible illness," meaning that a person who suffers from JIA does not display symptoms that are visually apparent, there is often a lack of understanding that surrounds this disorder. Occupational therapist Claire Dubouloz and her colleagues from the University of Ottawa and the Ottawa Hospital found an example of this in their study of individuals with rheumatoid arthritis. One participant stated, "... when I tell people that I have RA, they're shocked; they say 'my God, you look so good, you're not sick,...you don't have a disability.'" When prompted about this topic, another participant said, "(when you are) looking better than you are, (it) is difficult for others to accept your state of need" (Dubouloz et al., 2007). This disbelief or lack of understanding becomes an issue when trying to explain this invisible illness to friends, family, and other personal contacts. It also supports the decreased satisfaction with social relationships individuals with JIA often experience (Firth, 2011).

JIA can also impact one's moods and emotions. This is especially prevalent when the process of coping fails, as the individual may experience depression and lack of emotional

stability due to the unpredictable nature of the disorder (Karlsson et al., 2006). An individual may have feelings of isolation if their participation in daily activities decreases or if their friends and family do not understand or empathize with their experiences. In those with rheumatoid arthritis, depression is correlated with the “severity or degree of disability, functional loss, pain, and occupational deprivation” (MacKinnon et al., 1998). This implies that treatment that improves function, coping skills, and participation in occupation may help to alleviate the depressive symptoms of individuals with JIA.

Current Treatment

Currently, those with JIA are typically under the care of a primary physician, a rheumatologist, and often a physical therapist. A rheumatologist is a specialist who looks specifically at individuals with arthritis or other conditions of the bones, muscles, and joints. They, along with a team of specialized nurses, prescribe medication to treat the physiology of the individual with the goal of achieving a state of remission (Macedo et al., 2009).

There are a variety of medications that are used to treat both the symptoms and the underlying cause of JIA. These include non-steroidal anti-inflammatory drugs (NSAIDs), intra-articular steroid injections, disease-modifying anti-rheumatic drugs, and glucocorticoids. NSAIDs, including naproxen and ibuprofen, are typically the first treatment attempted because they have few side effects. They manage pain and inflammation by inhibiting an enzyme called cyclo-oxygenase which forms prostanoids that are in part responsible for the inflammatory response. Intra-articular steroid injections may be used to treat those who do not respond to NSAIDs. These injections prevent or fix contractures and prevent the leg length discrepancy that is sometimes seen in the JIA population (Dannecker & Quartier, 2009). Individuals requiring

more aggressive treatment may be prescribed disease-modifying anti-rheumatic drugs. The most common of these drugs is methotrexate. This works by suppressing the overactive immune system and has side effects of elevated liver enzymes, nausea, and vomiting (Albrecht & Ladner, 2010). The use of glucocorticoids is usually limited to those experiencing very severe symptoms or to those who only need it for immediate relief as they are waiting for other treatments to take effect (Dannecker & Quartier, 2009). Medications are a standard and usually first-line intervention used with those with JIA and similar conditions.

In addition to medications, referrals to physical therapy are common for individuals with JIA. Physical therapists tend to treat using therapeutic exercises, modalities, splinting, and education on joint protection techniques to prevent deformity. Exercises utilized may include resistive and range of motion exercises (Cakmak & Bolukbas, 2005). The benefits of exercise guided by a physical therapist are generally a decrease in joint pain, an increase in mobility and strength, and decreased risk of cardiovascular disease (Firth, 2011). Despite the physical improvements that are caused by exercise-based interventions, these exercises alone do not always result in increased quality of life (Arvidsson, et al., 2011).

Physical therapists may educate their patients with JIA regarding joint protection. This consists of techniques used in everyday life that can prevent deformity by decreasing stress on affected joints (Cakmak & Bolukbas, 2005). For example, if a person's wrists and hands are affected by JIA, they may be instructed to carry a grocery bag in the crook of their elbow, eliminating stress on their more vulnerable joints. Those with JIA may also be educated about proper footwear to decrease impact on knees and hips and stretching to maintain range of motion (Cakmak & Bolukbas, 2005).

Modalities used in physical therapy include cold and heat therapy, ultrasound, and massage (Firth, 2011; Cakmak & Bolukbas, 2005). Cold therapy, also called cryotherapy, is often applied using ice packs and is used to constrict the blood vessels in the affected area to reduce inflammation (Cakmak & Bolukbas, 2005). It has long been used as an analgesic that has been shown to raise the pain threshold of individuals with idiopathic arthritis for a short time after its application (Curkovic, 1992). Heat treatment helps to facilitate flexibility in joint capsules and tendons, alleviates pain and stiffness, and decreases muscle spasms. Ultrasound is a modality used that creates heat deep inside the tissues in order to facilitate similar symptom alleviation (Cakmak & Bolukbas, 2005).

Splinting can also be completed in physical therapy and has different purposes depending on the needs of the individual. A resting splint is used to immobilize the joint temporarily so that inflammation can decrease. In this splinting technique, positioning to maximize function is targeted in order to prevent contractures as well as maintain performance in everyday activities (Cakmak & Bolukbas, 2005). Dynamic splints contain at least one component that produces a constant force. This applied force helps to increase the passive range of motion of a particular joint while providing support (Lashgari & Yasuda, 2013). If the joint needs to be protected throughout activity, a physical therapist may mold a functional splint to provide extra support without limiting function. Gradual casting, which forces the maximal extension that the joint will allow, may be used in order to improve range of motion over time in cases that are more severe (Cakmak & Bolukbas, 2005).

An alternative and less common intervention used with those with JIA and similar conditions is massage therapy. After learning the correct techniques, the person may massage themselves during symptomatic periods or a family member or loved one may give the massage.

When this is done between fifteen and thirty minutes each day, it can result in decreased pain and anxiety (Field et al., 1997). Massages may also be done by a physical therapist along with heat to prepare the client for stretching exercises (Cakmak & Bolukbas, 2005).

ICF Model

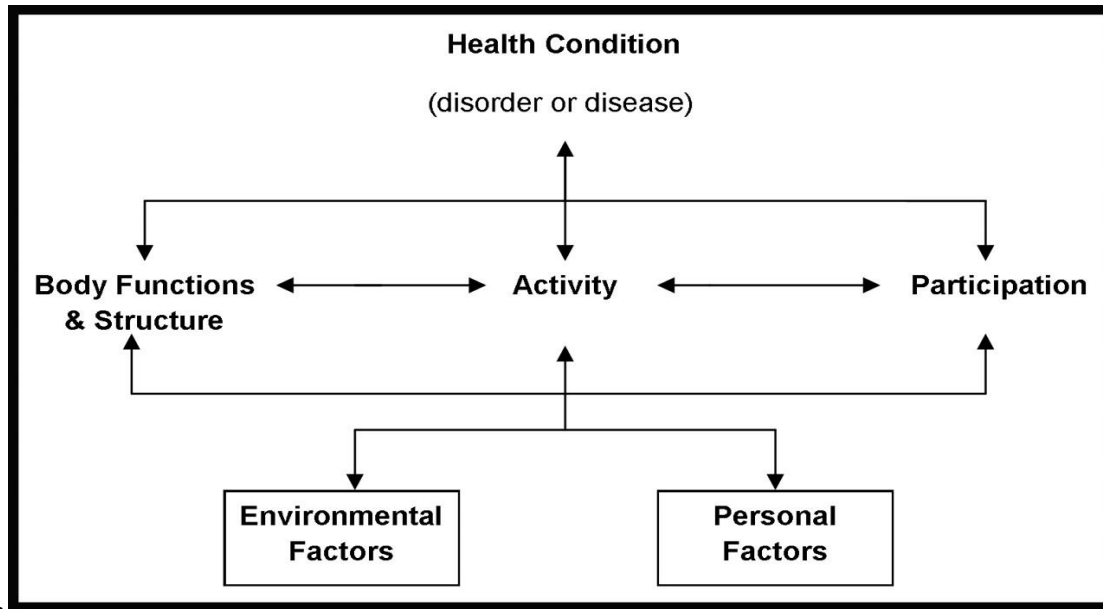


Figure 1. A visual representation of the ICF model. From World Health Organization (2001). International classification of functioning and disability. WHO. p18.

The International Classification of Functioning and Disability (ICF) model was developed by the World Health Organization (WHO) to conceptualize health and disability universally across health care disciplines (2001). This framework utilizes the biopsychosocial model, meaning that it views each person holistically, in light of the biological, psychological, and social components that contribute to their health. A person’s functioning is viewed as dynamic and multidimensional, consisting of the interactions between an individual’s body functions and structures, environmental factors, and personal factors. The person’s body

functions and structures affect participation and all of the involved factors impact the person’s success in a particular activity (WHO, 2001). Participation as part of the ICF model is highlighted in the field of occupational therapy as a targeted outcome of intervention as well as the means through which it is administered.

Table 1

ICF Terms as Defined by the World Health Organization

ICF Term	Definition
Body functions	The physiological functions of body systems (including psychological functions).
Body structures	Anatomical parts of the body such as organs, limbs and their components.
Impairments	Problems in body function and structure such as significant deviation or loss. The execution of a task or action by an individual
Activity	
Participation	Involvement in a life situation
Activity limitations	Difficulties an individual may have in executing activities
Participation restrictions	Problems individuals may experience in involvement in life situations
Environmental factors	The physical, social, and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning

Source: WHO 2001

Needs Assessment

While the World Health Organization views an individual holistically, current treatments for JIA and related conditions focus mainly on the physical body. While physical therapy and medication can result in physiological benefits, they do not address the psychosocial dimensions

or the functional implications of the disorder. This results in the residual dissatisfaction with certain domains and perhaps reduced quality of life (Karlsson et al., 2006).

In an effort to justify occupational therapy services for clients with rheumatoid arthritis, Cranitch conducted a study that found that there were significant gaps in treatment (2003). The personal factors that were commonly overlooked in these individuals included how to manage their symptoms, with 63% saying that they did not have any strategies to cope with pain other than medication. Patients were also not being issued or taught to use adaptive equipment or strategies (Cranitch, 2003). Treatment with medication and physical therapy alone may neglect the environmental aspect of a person's functioning, as home assessments are often conducted by occupational therapists.

Sometimes physicians do not always perceive their patient's needs in the same way that the patients themselves do, which could result in difficulty getting the proper services and support (Cranitch, 2003). In one study, physicians were surveyed about how frequently they would prescribe physical and occupational therapy to a patient with arthritis. The researchers found that physicians were much more likely to send patients to physical therapy than occupational therapy. Even so, they referred patients with osteoarthritis to occupational therapy significantly more than they did patients with any form of rheumatoid arthritis (Feldman et al., 2010).

Another potential cause for gaps in treatment of individuals with JIA and related conditions is the issue of funding. In the United States, about 75% of total health care spending is used for the treatment and management of chronic conditions such as JIA (Shi & Singh, 2012). For this reason, it may be challenging to justify even more services for this population without

evidence of significant impact. At the same time, there has been a worldwide reduction of healthcare spending in the 21st century, making it difficult to pay for services that may help to improve quality of life (Cranitch, 2003). This makes research about quality of life important, as it can inform third party payers about the need for services such as occupational therapy.

Role of Occupational Therapy

The occupational therapy framework was in part based upon the ICF model, viewing an individual more holistically. Occupational therapists are to consider the environment, occupation, and person, which parallels the ICF's environmental factors, activity and participation, and personal factors, body structures, and body functions respectively (AOTA, 2014b; WHO, 2001). More specifically, occupational therapists focus on the participation and health aspects of the ICF framework when planning and carrying out treatments (AOTA, 2014a). According to the official document regarding scope of practice by the American Occupational Therapy Association (AOTA), the scope of occupational therapy includes both the domain, or the focus, and the process, which refers to how these services are delivered (2014a). The domain of occupational therapy addresses the everyday life activities that the client finds purposeful and meaningful through which they can complete their roles. The process is client-centered and involves the evaluation, intervention, and targeting of outcomes (AOTA, 2014b)

The most recent edition of the Occupational Therapy Practice Framework (OTPF), which speaks to the process of occupational therapy treatment and the domains it serves, contains eight areas of occupation. They are activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, leisure, work, education, play, and social participation. ADLs refer to self-care activities such as bathing, dressing, and grooming, while IADLs include

activities that are not so fundamental but are required for independent living, such as home maintenance, medication management, and meal preparation (AOTA, 2014b).

The OTPF also outlines client factors, performance skills, performance patterns and the context and environment. Client factors consist of the individual's values, beliefs, and spirituality, as well as the body functions and body structures that affect their participation in activities. Performance skills are components of an action that can relate to one's motor, process, or social interaction abilities. For example, in order to get dressed, a person must be able to choose proper clothing, reach, bend, and sequence the order of clothing to be donned, among many other performance skills. Performance patterns are the habits, routines, roles, and rituals a person assumes as they participate in various activities. The context of the client can make a large impact on their functioning and, as a result, is an important consideration when practicing occupational therapy. The OTPF guides occupational therapy practitioners to look at the physical and social aspects of the environment, as well as the cultural, personal, temporal, and virtual contexts in which the client is immersed (AOTA, 2014b).

Occupational therapy also directly addresses quality of life in the context of meaningful activities. As stated in the OTPF, occupational therapy interventions are geared toward "achieving health, well-being, and participation in life through engagement in occupations." Quality of life is a specific outcome defined in the OTPF as, "a dynamic appraisal of the client's life satisfaction, hope, self-concept, health and functioning, and socioeconomic factors" (AOTA, 2014b). As quality of life can be assessed and addressed by occupational therapy through the context of meaningful activities, receiving occupational therapy services may help to improve the quality of life of populations such as those with JIA.

Current interventions for those with JIA include medication and sometimes physical therapy, which both focus primarily on the physical symptoms of this condition. However, previous literature suggests that those with JIA face other significant challenges related to their overall life satisfaction that cannot be managed through medication and physical therapy alone. As a result, there may be a gap in healthcare services to this population that neglects quality of life. Occupational therapy specifically addresses quality of life and therefore may be able to alleviate some of the challenges individuals with JIA face related to life satisfaction. This study aims to 1) analyze the quality of life of individuals with JIA and related conditions, 2) identify quality of life needs and strengths in this population, and 3) discuss identified needs in light of the potential role of occupational therapy.

Methodology

Sample

Adults with JIA and similar conditions were recruited through convenience snowball sampling, starting with personal contacts that have had past and/or current involvement with the Eastern Pennsylvania Chapter of the Arthritis Foundation. Following contact, fourteen individuals participated in this survey. Seven of these had JIA alone, one had a dual diagnosis of JIA and fibromyalgia, and one was diagnosed with JIA and psoriatic arthritis. The remaining five participants had diagnoses of juvenile dermatomyositis, systemic lupus erythematosus, ankylosing spondylitis, or Wegner's granulomatosis. The age of the participants ranged from twenty to thirty two with thirteen participants identifying as females and one identifying as a male.

Survey Instrument

The survey instrument utilized was the shortened version of the World Health Organization's Quality of Life (WHOQOL-BREF) assessment. It is person-centered and has been designed and tested for use with people who have a wide range of health conditions (Skevington et al., 2003). This tool is intended to measure the quality of life in the domains of physical health, psychological health, social relationships, and the environment. The WHOQOL-BREF asks participants to rate items under these domains to assess individuals' feelings, frequency and extent of experiences, and satisfaction on a Likert-type scale. It also asks for demographic information such as gender, date of birth, and any illnesses one may have (WHO, 1996). The assessment itself has good scores for validity and good to excellent scores for reliability, and has been determined to have a place "among the leading generic quality of life instruments" (Skevington et al., 2003).

Procedure

Following approval from Elizabethtown College's Institutional Review Board, participants were contacted through social media and provided with a link to SurveyMonkey, which contained the consent form for this study. Upon providing electronic consent, they were sent a second link to SurveyMonkey, which contained all items from the WHOQOL-BREF. Participants were instructed to answer all questions with which they felt comfortable and to omit any they wished not to answer.

Measures of central tendency were computed for each of the twenty-six items on the WHOQOL-BREF and means and modes of the items were analyzed for patterns. Individual scores were then calculated in the domains of physical health, psychological health, social

relationships, and the environment. These raw scores were converted to the transformed scores, as described in Table 4 of the WHOQOL-BREF Introduction, Administration, and Scoring Guide. The transformed domain scores for each individual were then analyzed collectively using descriptive statistics. The transformed mean scores for each domain as well as the mean scores for each item were listed from lowest to highest score. Items with mean scores of less than 3.5 were considered quality of life needs, as this indicates moderate satisfaction or less. The items with the highest five mean scores were considered quality of life strengths. As the WHOQOL-BREF only offers a scale for transformed scores for the four domains, the mean scores of each item were recorded and compared as raw scores (1-5 on the Likert Scale).

Results

The individual items that were considered quality of life needs in order from lowest to highest mean score are as follows: dissatisfaction with sleep (2.71), lack of opportunities for leisure (2.86), having negative feelings such as blue mood, depression, or sadness (3.0), problems accepting bodily appearance (3.21), difficulties concentrating (3.29), and requiring medical treatment to function (3.29). The five items in which participants had the highest satisfaction were considered quality of life strengths. These include having adequate transportation (4.36), finding their life to be meaningful (4.29), enjoying life (4.29), having information available to them (4.21), and getting support from friends (4.21).

Of the six quality of life needs identified, two items (sleep and requiring medical treatment) were in the domain of physical health, three (negative feelings, bodily appearance, and concentrating) were in the psychological health domain, and one (opportunities for leisure) fell into the environmental domain. There were no items on the WHOQOL-BREF in the social

relationships domain that were considered quality of life needs according to the parameters of this study. In terms of the biopsychosocial model of the ICF, there were more quality of life needs in the biological and psychological aspects of the surveyed individuals than there were in the social areas.

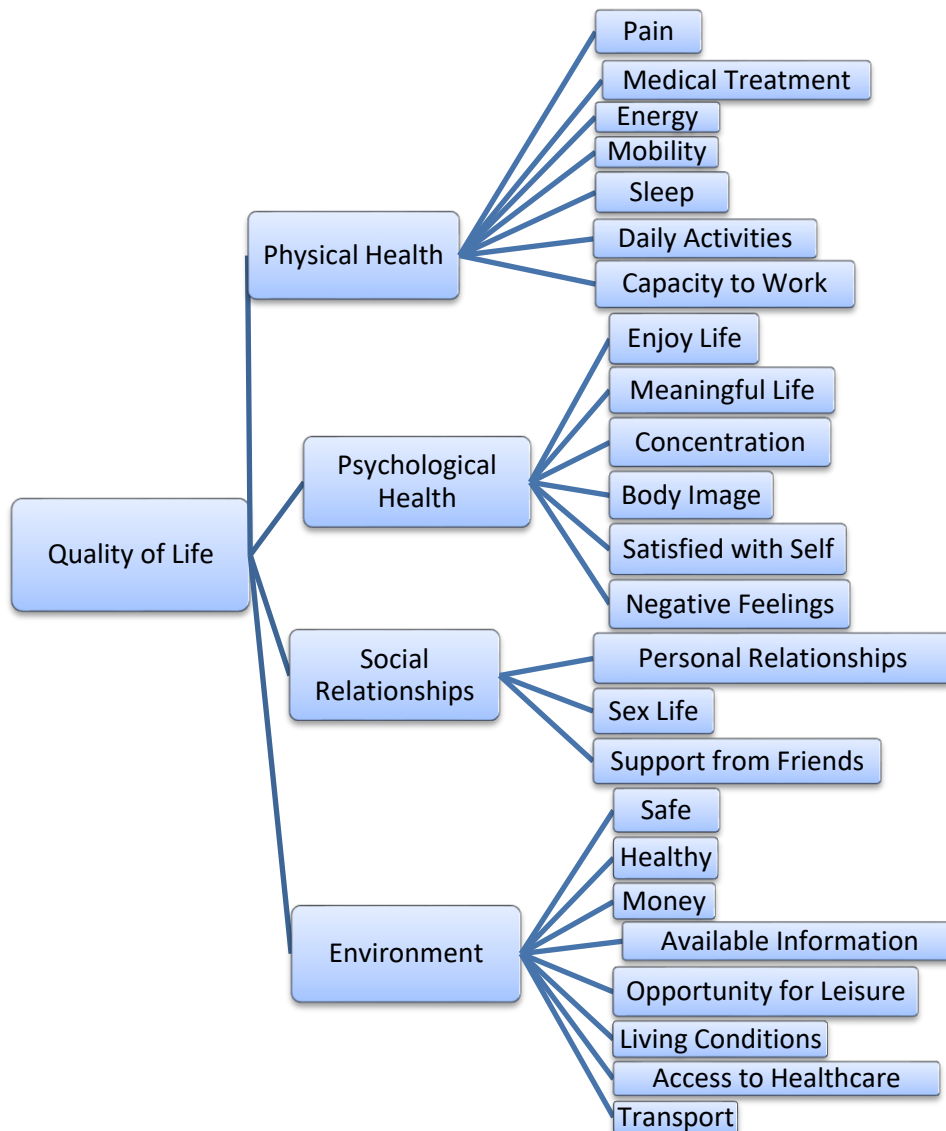


Figure 2. The above figure depicts WHOQOL-BREF's four domain scores that describe overall quality of life and all of the items that fall under each domain.

Table 2 outlines the descriptive statistics for each one of the four domain scores. As evidenced by this data, the mean score for the domain of social relationships is the highest (77.714), followed by the environment (70.571), psychological health (65.286), and physical health respectively (61.357).

Table 2

Descriptive Statistics for the Four Domains of Quality of Life

	Mean	Mode	Median	SD	Range	Min	Max
Physical Domain	61.357	44	63	18.599	63	25	88
Psychological Domain	65.286	69	69	14.199	50	38	88
Social Domain	77.714	69 & 94	81	21.406	69	31	100
Environmental Domain	70.571	56	69	13.574	44	56	100

Discussion

Domain Scores

The literature supports the findings of this study especially in relation to the domain scores. As symptoms of JIA include joint pain, fatigue, inflammation, range of motion limitations and potential degeneration and deformity, it makes sense that quality of life would be lowest in the physical domain (Karlsson et al., 2006). However, only two of the identified quality of life needs fell into this domain, as the effects of JIA are not limited to its primary physical manifestations. This is shown by the quality of life score in the psychological domain, which was the category that contained the most quality of life needs. As stated in the literature, depression and other psychosocial complications are common in those with JIA and similar conditions (Cranitch, 2003). These psychological factors are often not addressed in traditional interventions

with this population, which may relate to the residual psychological quality of life needs. The environmental domain contained one quality of life need and the social relationships domain did not have any quality of life needs. While they may pose quality of life issues for some individuals with JIA, this data indicates that these two domains were not a large source for quality of life needs for the participants surveyed.

Implications for Occupational Therapy

Interestingly, all six of the identified needs fall within the scope of occupational therapy according to the Occupational Therapy Practice Framework (OTPF). Dissatisfaction with sleep was considered the greatest quality of life need, as it was the item with the lowest mean score. This need may be caused by the symptom of joint pain, which is classified as an impairment of body function that is often experienced by those with JIA and related conditions. If an individual is in pain, it may be difficult to relax or find a position in which they are comfortable enough to sleep. As outlined in the literature review, the OTPF states that sleep is an area of occupation that can be addressed by occupational therapy (AOTA, 2014b). One occupational therapy intervention that addresses sleep is known as sleep hygiene. This helps the individual to establish a nightly routine that relaxes them as well as an environment that is more conducive to sleep (Koketsu, 2013). Additionally, occupational therapy can help to directly reduce the pain that impacts sleep by teaching those with JIA different coping skills that fit their needs (Hofman, 2006).

The second greatest need discovered through this study was a lack of opportunities for leisure. Like sleep, leisure is an area of occupation identified in the OTPF (AOTA, 2014b). Individuals with JIA may not have the opportunity for leisure if they are experiencing pain or

fatigue and, as stated in the literature, two thirds of those with JIA have completely given up a leisure activity they enjoyed (Wikstrom et al., 2001). Because this area of occupation is not seen as necessary, leisure is often the first aspect of a person's participation from which they withdraw. However, it is important to one's overall health and well-being and is one of the most significant predictors of life satisfaction overall (Krishnagiri & Southam, 2013). Occupational therapists can teach pain management and energy conservation techniques to improve an individual's participation in their preferred leisure activities. If a person does not have the body functions or performance skills necessary to complete these successfully, the preferred leisure activity could be adapted or new leisure options could be explored (Krishnagiri & Southam, 2013).

Occupational therapy can address individuals who often experience negative feelings such as blue mood, sadness, or depression. These and other psychosocial issues can manifest in those with JIA and related conditions as a result of feeling decreased competence and a lack of control over their disease (Karlsson et al., 2006). Occupational therapists are trained to be aware of one's perceived self-efficacy and tailor interventions to ensure success. Being able to participate in meaningful activities successfully can reduce feelings of sadness or depression. Cognitive behavioral therapy is a strategy that can be utilized in occupational therapy that helps the client to understand how their thoughts influence their emotions and actions (Cara & MacRae, 2012). If the individual can be taught to control negative thoughts through occupational therapy, they may experience these negative feelings less often, thus improving quality of life.

Difficulty accepting bodily appearance was the fourth quality of life need reported by participants in this study. It is common for those with any physical disability, not only those with JIA, to struggle with negative body image. Cognitive behavioral therapy can be used as an

intervention to help these individuals move beyond negative self-talk and recognize how their thoughts influence their feelings (Cara & MacRae, 2012). Increasing awareness about how one's thinking perpetuates difficulties accepting bodily appearance may help to mitigate the severity of body image issues.

Another quality of life need that could be addressed by occupational therapy is difficulties with concentration. This need may be attributed to the pain and fatigue experienced by the JIA population, which may cause a discomfort that makes it difficult to focus. Attention, which includes concentration according to the OTPF, is classified as a body function. Occupational therapy can intervene with those who are having problems concentrating by limiting distractions in the environment (AOTA, 2014b). This may help to compensate for the person's poor concentration. Another strategy could be to address the cause of the concentration difficulties. If they are experiencing pain and fatigue, an occupational therapist could teach the individual pain management and energy conservation techniques.

The final quality of life need identified in this study was requiring medical treatment to function. This was supported by the literature as 63% of individuals with JIA did not have any strategies to cope with pain other than medication (Cranitch, 2003). Managing pain levels is important to one's ability to participate in meaningful activities and is therefore addressed by occupational therapy. An occupational therapist can help the person explore what tasks, time of day, or environmental circumstances cause them more pain and work collaboratively with the client to help minimize these occurrences. Coping skills such as using therapeutic modalities, taking a hot shower, meditation, and yoga have all been found to be effective in reducing pain for some individuals (Hofman, 2006). Occupational therapy, as it is a client-centered profession,

can help those with JIA and related conditions to find the mechanism for pain management that works best in their lives.

Limitations and Considerations

This study has a number of limitations that impact the value of its results. Firstly, the small sample size may have reduced the ability of this data to be generalized to the entire population of those with JIA and similar conditions. Participants were recruited through convenience snowball sampling and all had current and/or previous involvement with the Eastern Chapter of the Arthritis Foundation which also affects the external validity of the research. Because there was no control group, there was no way to compare the quality of life scores of those with JIA to those without this disorder. The study also did not consider whether or not the participants were in a state of exacerbation or remission regarding their symptoms, as this could have affected the results.

Because participants in this study were between the ages of twenty and thirty-two and JIA and similar juvenile conditions must be diagnosed prior to the age of sixteen, the needs identified have carried into adulthood, years after the diagnosis. This implies that the quality of life needs identified are generally long-lasting and may remain chronic issues if there is no direct intervention. As JIA is a type of arthritis, which comprises the largest disability population of non-institutionalized adults, these ongoing quality of life needs may be widespread, making them important to address (Cranitch, 2003).

Despite the findings of this research, more data is needed to pinpoint quality of life needs experienced by those with JIA. This study should be repeated with a larger sample that better represents the entire population of those individuals who have been diagnosed with JIA and

similar conditions. Future research must be done in order to confirm the quality of life needs discovered in this study, identify more quality of life needs, and compare the quality of life of those with JIA to the general population. A comparison between quality of life needs of adults with JIA and those of children who have recently been diagnosed would inform of how these needs change across the lifespan. It would also reveal which needs, if any, resolve during the adjustment process. Potential occupational therapy interventions outlined for each of the quality of life needs should also be tested for their effectiveness in improving overall quality of life for individuals with JIA.

Assessing quality of life in those with JIA is important to understanding that their needs go beyond their physiological state of being and can also include psychological, social, and environmental components. Awareness of the impact that JIA has on the physical, psychological, social, and environmental domains allows professionals to better address their clients with this and similar conditions. With more evidence to support this, healthcare providers can supply holistic interventions that consider each individual's quality of life needs. As a client-centered practice that addresses the identified needs within its scope, occupational therapy may help to improve the quality of life in those with JIA and similar conditions.

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