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Developing a Juvenile Arthritis Transition Program for Teens

Nicole M. Meert

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Under the direction of the faculty capstone advisor:

Rebecca Barton, DHS, OTR, FAOTA

A Capstone Project Entitled

Developing a Juvenile Arthritis Transition Program for Teens

Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

By

Nicole M. Meert

OTS

Approved by:

Faculty Capstone Advisor

Date

Doctoral Capstone Coordinator

Date

Accepted on this date by the Chair of the School of Occupational Therapy:

Chair, School of Occupational Therapy

Date

Abstract

Over 300,000 children in the United States have been diagnosed with some form of juvenile arthritis. However, there are fewer than 350 board-certified practicing pediatric rheumatologists in the United States, with only 25 percent of children living with juvenile arthritis seeing a pediatric rheumatologist to manage their treatment. The purpose of this project was to develop transition program recommendations for teens with juvenile arthritis transitioning to adult care in the United States. The main models used in this project were the Precaution Adoption Process Model and the Person-Environment-Occupation-Performance Model. An outcome tool was developed to gather information on several topics important to the transition process such as disease management self-efficacy, health distress, current behaviors when visiting a doctor, and depression. There were a total of 4 respondents to the survey with an average Function score of 54 and an average Dysfunction Score of 35.5. Through a literature review, it was determined that it is important to acknowledge that the teens with arthritis have autonomy in the decision-making process when it comes to their health care. Therapists need to allow the client to decide when it is time to progress through each stage in the transition process, as well as provide the tools necessary to become independent with their new role, including providing the opportunity for trial and error, exploring various coping strategies, instilling the skills of time and medication management, and teaching them how to seek out reliable resources as they continue throughout their life span with their chronic condition.

Developing a Juvenile Arthritis Transition Program for Teens

Over 300,000 children in the United States have been diagnosed with some form of juvenile arthritis (Arthritis National Research Foundation, n.d.). With fewer than 350 board-certified practicing pediatric rheumatologists in the United States, only 25 percent of children living with juvenile arthritis are seen by pediatric rheumatologists (Arthritis Foundation, n.d.). The remaining 75 percent are seen by adult rheumatologists or pediatric rheumatologists that lack adequate training to treat children with juvenile arthritis along with their additional comorbidities that they may have (Arthritis Foundation n.d.). Due to recent medical advances and the development of new medications, the predicted 10-year survival rates of chronic pediatric rheumatological diseases is now over 95 percent (Anelli et al., 2017). This has led to a recent push internationally for a transition program for children with juvenile arthritis. There is currently a large body of research on transitioning children, their parents, and the expectations surrounding the transition, however, there is limited research investigating transition programs themselves. There are several established transition programs in Canada and Europe, however, there is very little research for the United States.

Rettig and Athreya (1991) determined that a structured transition program is needed to ensure that children who transitioned were not lost due to lack of follow-up with their adult rheumatologist. A study performed by Staa, Jedeloo, Meeteren, & Latour (2011) confirmed that transitioning is a logical step, but parents are concerned due to the culture gap between pediatric and adult care. The researchers stated that more preparation is needed for children and their parents before the transition occurs (Staa, Jedeloo, Meeteren, & Latour, 2011). Although there is a worldwide shortage of qualified pediatric rheumatologists there is not a difference in outcomes based on whether children were treated by a pediatric rheumatologist or a general pediatrician,

however, it is still imperative to that education is provided to the children and their families regarding their transition to adult care (Miyamae et al., 2014). This is due to the multitude of studies that indicate the transition process is flawed due to inadequate staff training; lack of resources; financial difficulties; anxiety of the doctors, patients, and parents; and patients often feeling abandoned or rejection, also, experiencing a difficult transition may lead to high drop-out rates and poor medical outcomes (Anelli et al., 2017). In 2007, the American Academy of Pediatrics listed transitioning youth with special healthcare needs to adult care as one of their top 10 priorities (Anelli et al., 2017).

Rettig & Athreya (1991) completed a study and determined that the primary obstacle with developing a comprehensive transition program is the lack of funding for services of the transition team. Insurance companies are less likely to reimburse for services provided by a transition nurse or transition social worker (Rettig & Athreya, 1991). However, due to the client-centered model of practice and collaborative team approach that occupational therapy utilizes, occupational therapists are qualified to assist with transitions due to our scope of practice (Orentlicher et al., 2017). The Occupational Therapy Practice Framework: Domain and Process (3rd ed) guides therapists to examine client factors, performance patterns, roles, and contexts when discussing transitions (American Occupational Therapy Association [AOTA], 2014). Due to occupational therapists' extensive knowledge of task analysis and environmental adaptations they can apply their knowledge to assist with transitioning into secondary education and assuming adult roles either through the public education system or a community-based setting (Orentlicher et al., 2017).

The purpose of this project was to develop transition program recommendations for teens with juvenile arthritis transitioning to adult care. The main models used are the Precaution

Adoption Process Model (PAPM) and the Person-Environment-Occupation-Performance Model (PEOP). These two models were selected based on how each model views the decision-making process of a person and what factors the person desires to modify or change to promote optimal occupational participation and performance. The PAPM has its roots in the public health field and was originally designed to demonstrate how people respond to provided information based on a newly discovered "threat to their health" (Weinstein, Sandman, & Blalock, 2008). The idea of this model is that a new "threat" (in this case the young adults being made aware that they must eventually transition to an adult rheumatologist), would not be known unless the person is consciously aware of the harm (rushed into a transition, not ready for a transition, feelings of abandonment, or lack of follow up with their new doctor) (Weinstein, Sandman, & Blalock, 2008). The seven stages of this model include Stage 1: Unaware of the issue, Stage 2: Unengaged by the issue, Stage 3: Deciding about acting, Stage 4: Deciding not to act, Stage 5: Deciding to act, Stage 6: Acting, and Stage 7: Maintenance (Weinstein, Sandman, & Blalock, 2008). In stage 4, if the person decides not to act, then the process is complete (Weinstein, Sandman, & Blalock, 2008). If the person decides to act, the process continues to stage 5 and ultimately culminating in stage 7 (Weinstein, Sandman, & Blalock, 2008). This model is laid out in a linear fashion, but the process is not necessarily linear in nature. A person may be in stage 6 and then experience a setback and move to stage 4 for a period (Weinstein, Sandman, & Blalock, 2008). The PAPM model is the best fit for introducing the topic of transition to young adults, because it recognizes that everyone is at their own unique spot in the process and their priorities or stage may change as their life/symptoms change. This model also recognizes the autonomy of the person deciding not to act. The PEOP model has its roots in occupational therapy (Cole & Tufano, 2008). This model focuses on the client, relevant intrinsic and extrinsic factors,

environment, occupations, and the performance of occupations (Cole & Tufano, 2008). The PEOP model states that a positive change happens when a positive cycle of motivation is created due to intrinsic and extrinsic rewards (Cole & Tufano, 2008). The PEOP will be used to help guide the decision-making process for recommendations made for the transition program. The topics that will be discussed, in the transition program, will focus on adaptations/modifications that can occur now as well as adaptations and modifications that may need to occur in the future. This model is the best fit, because it does not stress one specific area where improvements must be made to improve the person's overall occupation performance.

Juvenile Arthritis is a chronic health condition that changes throughout a person's life and a model to address adaptations/modifications must be able to change as well. Since Juvenile Arthritis changes throughout the young adults' life it was important to select models that are not strict in their order or process. By giving the participants the option to not act, their autonomy is being respected. The PEOP model provides the flexibility to discuss different adaptations/modifications, for example, ADL equipment, energy conservation, ergonomics, adaptive school/work equipment, and leisure pursuits. By not limiting the topics of discussion to just occupations or just the environment the transition program can cover more topics and additional resources for when the young adults are ready to consider other options such as a shower chair or modified desk/car.

Screening and Evaluation

A needs assessment and literature review were conducted to determine the needs of the Indiana Arthritis Foundation in assisting young adults and teenagers diagnosed with juvenile arthritis transitioning to adult care. A literature review revealed that there are several successful transition programs throughout the world including the ONTRAC and Good2Go programs in

Canada, however, there is a significant lack of research being conducted in the United States (Grants & Pan, 2011). Therefore, it was determined that there is a need for a transition program specific for teens and young adults in the United States diagnosed with juvenile arthritis that are transitioning to adult care.

According to the Arthritis Foundation, the transition process should ideally begin at 12-14 years of age and culminate at ages 23-26 (Arthritis Foundation, 2018f & 2018a). The screening process will include those that have been diagnosed with juvenile arthritis, are between the ages of 13 and 21, and reside in Indiana. The participants were recruited from using the Arthritis Foundation database of past and current event participants.

This Doctoral Capstone project is unique in the sense that Occupational Therapy is currently not involved in the transition process (Arthritis Foundation, 2018a). Currently the only medical professionals involved are the pediatric and adult rheumatologists. This is in direct contrast to the role that occupational therapists have in transition planning for those in the school system with an Individualized Education Plan or IEP (Orentlicher et al. 2017). Occupational therapists assist clients with career exploration and assuming independent roles in their healthcare and social interactions (Orentlicher et al. 2017). However, many teenagers with juvenile arthritis do not have IEPs through school and do not receive this guidance as they transition.

Implementation Phase

Due to the lack of literature and knowledge concerning the topic of what to include in a juvenile arthritis transition program in the United States, it was determined that data needed to be collected concerning this topic. An online survey was selected as the best format to collect data, due to several factors including the quantity of surveys to be sent out, it was not feasible to send

out paper surveys with the risk of zero follow up. An additional factor was the ease to complete the survey, it is easier for those with fine motor and dexterity issues to complete a survey online than to fill it out with a paper and pencil. Therefore the best option for data collection was the electronic survey.

Online Survey

It was determined that no comprehensive survey existed that measures more than one component of patients' current self-efficacy for managing their disease and investigating their current mental health. Therefore, a comprehensive survey was created by adapting questions from multiple surveys from the Self-Management Resource Center tools, see Appendices A-E. These scales were noted to be used freely without permission. Section A, the scoring sheet, and function/dysfunction scales were added to the preexisting scales to make a comprehensive screening tool for the Juvenile Arthritis population. The completed screening is titled the Juvenile Arthritis Medical management, Self-efficacy, Symptom limitations, and Mental health Screen (JAMS-M Screen), a copy of the screen used can be found in Appendix F. The survey collected data on the subjects' actions when attending doctors' appointments, self-efficacy of the management of their arthritis, the impact of their arthritis on their social roles and activities, their current level of distress due to their health status, and their current level of depression due to their diagnosis.

The demographics section was added to collect relevant information including current age, gender, age of diagnosis, type of arthritis and type of doctor they are seeing for treatment to better categorize results. The current actions they complete while visiting their doctors was measured by using a 3 item 6-point Likert scale, see Appendix A (Self-Management Resource Center [SMRC], n.d.b). This scale was tested on 1130 subjects with chronic disease and 51

subjects were used for test-retest reliability, with an internal consistency reliability of .73 and a test-retest reliability of .89. (Lorig et al., 1996). The self-efficacy section of the survey consists of 8 items on a 10-point Likert scale adapted from the Arthritis Self-efficacy scale, see Appendix B (SMRC, n.d.a). This scale was tested on 175 subjects with arthritis and has an internal consistency reliability of .92 (Stanford Arthritis Self-Management Study). Their level of distress was measured by 4 items on a 6-point scale adapted from the Health Distress scale, see Appendix C (SMRC, n.d.c). This scale was tested on 1130 subjects with chronic diseases and 51 subjects for test-retest reliability with an internal consistency of .87 and test-retest reliability of .87 (Lorig et al., 1996). The impact of their arthritis on their social roles and activities was measured using 4 items on a 5-point Likert scale, see Appendix D (SMRC, n.d.e). This scale was tested on 1130 subjects with chronic disease and 51 for test-retest reliability with an internal consistency reliability of .91 and test-retest reliability of .68 (Lorig et al., 1996). Their current level of depression was measured on an 8 item 4-point Likert scale, see Appendix E (SMRC, n.d.d). This scale was tested on 1165 subjects with chronic conditions with an internal consistency reliability of .86 (Ory et al., 2013). These scales were selected due to their strong psychometrics and specificity for people with arthritis and chronic diseases. The scores from each section of the JAMS-M screen were combined in to a function score and a dysfunction score. The function score is calculated using the scores from the communication with physicians and arthritis self-efficacy sections, see Appendix F. Function scores can range from 8-95 points, with 8 indicating low function and 95 indicating high function. The dysfunction score is calculated using the scores from the social/role activity limitations, health distress, and depression sections. Dysfunction scores can range from 0-60, with 0 being no dysfunction and 60

being high dysfunction. With the two score, the scorer can determine which areas the client is having difficulty in and provide interventions accordingly.

The JAMS-M Screen was sent via email to 178 registered Indiana Arthritis Foundation past and present event participants between the ages of 13 and 21 years old. This age range was selected due to previous research that determined the transition process takes place during the ages of 13 to 21 (Arthritis Foundation, 2018e). The JAMS-M screen was also posted on an Indiana and Central Illinois Families Juvenile Arthritis Facebook page run by the Indiana Arthritis Foundation. The collected data was used to prioritize the topics of mental health and coping skills, self-efficacy, life skills needed for managing a chronic disease, and health literacy.

Staff Training and Education

Due to the Arthritis Foundation being an emerging setting for occupational therapy, the staff had limited knowledge on the role and benefits of occupational therapy for people with arthritis and how occupational therapy could specifically help with the transition process. While preparing for the annual walk the foundation holds, the staff made the decision to have an “Ask a Doc” area that included a chiropractor, massage therapist, physical therapist, and an occupational therapist. When it came time to create materials for this area describing what each professional could offer to the participants, the staff had limited knowledge of what occupational therapy could do to help those with arthritis throughout the lifespan. They knew that OTs can help with energy conservation and activity modifications as well as after joint replacement surgeries, but that is where their knowledge ended. Through the needs assessment process, it was determined that the staff would benefit from a presentation to address these gaps in knowledge. The presentation developed for the staff, covered topics including the role and benefits of occupational therapy in the treatment for people with arthritis, the differences between

occupational therapy and physical therapy, and common occupational therapy treatments for people with arthritis. The goal of this presentation was to increase the staff's knowledge and ability to advocate for occupational therapy services for those with arthritis, a copy of the presentation can be found in Appendix G.

Leadership

I had taken on several roles during this project including serving as a resource for the staff of the foundation, assisting with material development for their national Juvenile Arthritis Conference, and serving as an “expert” on transitioning. I had anticipated serving as a resource for the staff in several ways, including educating them and the people they serve on the benefits of occupational therapy and assisting with program development for transition program recommendations. I however, did not anticipate assisting with the National Juvenile Arthritis Conference. I had this amazing opportunity as a result discussing my journey with two people in charge of juvenile arthritis at the national office. I provided suggestions for social media activity designed to help those not attending the conference feel included. Using my skills from my undergraduate degree, I recommended a photo voice campaign to shed the light on what it is like to live with JA behind the scenes. The teens would post pictures and caption them to show what it is like, including showing how they cope with having JA or manage their many invisible symptoms.

Another role that I had not planned for, was becoming an “expert” on transitioning with juvenile arthritis. This idea happen by accident when I was looking for resources online for those with autoimmune diseases. I found several blogs about living with arthritis, but none of these were for children or teens transitioning to adult care, and many were written by people with many different life roles. However, none of them wrote about their transition to adjusting to their

diagnosis and none of them were written by a medical professional. Therefore, I took it upon myself to use my personal experiences and occupational therapy knowledge to write a monthly blog about various topics including energy conservation, vacationing, how to prepare for transiting to college, and mental health (Meert, 2018). My blog includes information from my perspective, helpful suggestions, and online resources to help the readers learn more, a copy of selected blog posts can be found in Appendix H.

Outcomes

As stated previously, a comprehensive survey was created by adapting questions from multiple surveys from the Self-Management Resource Center tools, see Appendices A-E. These scales were noted to be used freely without permission. Section A, the scoring sheet, and function/dysfunction scales were added to the preexisting scales to make a comprehensive screening tool for the Juvenile Arthritis population.

The JAMS-M Screen was sent via email to 178 registered Indiana Arthritis Foundation past and present event participants between the ages of 13 and 21 years old and posted on the Indiana and Central Illinois Families Juvenile Arthritis Facebook page run by the Indiana Arthritis Foundation. The JAMS-M Screen was completed by 4 female participants, with ages ranging from 13-21. Three out of the four participants have Juvenile Idiopathic Arthritis (JIA) Polyarticular, meaning that 5 or more joints are involved. One participant has Non-Ankylosing Spondylitis. A summary of the demographic data can be found in Table 1.

Table 1

Participant	Age	Type of Juvenile Arthritis	Age of diagnosis
1	19-21	Non-Ankylosing Spondylitis	12
2	13-15	JIA-Polyarticular (5+ joints)	2
3	16-18	JIA-Polyarticular (5+ joints)	15
4	16-18	JIA-Polyarticular (5+ joints)	2

The participants' scores from each section and the means scores were calculated. A summary of the scores can be found in Table 2. The mean score for communication with physicians was 7.75. The participants' score demonstrates that they all demonstrate positive communicate with their physicians at appointments. The mean score for arthritis self-efficacy was 46.25. Participants' scores for arthritis self-efficacy demonstrate moderate self-efficacy with managing their arthritis symptoms. The function scale scores were 52, 45, 62, and 57 respectively. These scores demonstrate that the participants are functioning well despite their diagnoses. The mean score for social/role activities limitations was 9. Participants' scores for social/role activity limitations fell into the moderate limitations range due to disease activity. This demonstrates a need for activity/environmental modifications education, as well as medication management and coping strategies education, to decrease the participants social/role activity limitations impacting their occupations and occupational performance. The mean score for health distress was 13.75. Participants' scores ranged from minimally to highly impacted due to health distress. This demonstrates the need for health literacy and coping skills education, to decrease the amount of health distress the participants are experiencing. The mean score for depression was 12.75. The participants' scores ranged from minimal to moderate depression symptoms. This demonstrates a need for coping skills education to decrease the participants depression symptoms. The dysfunction scale scores were 28, 36, 27, and 51 respectively. These scores demonstrate that the participants are experiencing some limitations in managing their symptoms either due to disease activity or depression/ health distress, as well as that they would benefit from the interventions and education that occupational therapy services could provide as listed previously in this section.

Table 2

Communication with Physicians	Participant	Score	Mean 7.75	Social/Role Activity Limitations	Participant	Score	Mean 9
	1	7			1	8	
	2	5			2	7	
	3	11			3	9	
	4	8			4	12	
Arthritis Self-efficacy	Participant	Score	Mean 46.25	Health Distress	Participant	Score	Mean 13.75
	1	45			1	9	
	2	40			2	17	
	3	51			3	9	
	4	49			4	12	
Function Scale	Participant	Score	Mean 54	Depression	Participant	Score	Mean 12.75
	1	52			1	11	
	2	45			2	12	
	3	62			3	9	
	4	57			4	19	
				Dysfunction Scale	Participant	Score	Mean 35.5
					1	28	
					2	36	
					3	27	
					4	51	

My online blog has received positive feedback so far, there are several families that follow my posts and the Arthritis Foundation has received positive feedback from several nurses at Riley Children’s Hospital.

Discontinuation

The staff education was a onetime presentation that I left with the staff for them to use when needed and when new staff members are hired. I plan to submit my recommendations for a transition program to the Indiana Arthritis Foundation to take into consideration. My hope is that either another occupational therapy student will continue the process by developing the program, or that I will develop it after I have been practicing for at least a year. As for the blog, I plan to continue posting at least once a month. The blog has proven to be beneficial based on the feedback I have received and I want it to be out there and ready for the teens to use when they begin their own transitions. I also plan to continue to be a resource for the foundation after graduation because of the experiences that I have had as a direct result of this doctoral

experience. Also, the teens will continue to transition in various aspects of their lives and will need continual support.

Overall Learning

I have had the opportunity to interact with the clients, in this case children with arthritis, through various mediums including verbally at meet and greets and written through blog/social media posts. The meet and greets were designed to meet others with arthritis for networking and social support through shared experiences and sharing their personal stories. I have written several blog posts sharing my personal experiences to provide motivation for others transitioning to adult care, and to provide insight for health professionals working with teens and young adults to manage their chronic conditions. I have also had the opportunity to interact with several colleagues at the local office and national office during conference calls and weekly video meetings. During my time I was able to attend several public events for the Arthritis Foundation including health fairs, fundraisers, charity walks/runs, and presentations. Completing this project in an emerging practice area has allowed me to use my occupational therapy knowledge to advocate for the populations served by the Arthritis Foundations as well as investigate the needs of the teens and young adults with juvenile arthritis transitioning to adult care. Through this learning experience, I have been able to conduct preliminary research into the topic of developing a program for teens with juvenile arthritis transitioning to adult care in the United States. I have been able to perform a brief survey that confirms my personal experiences that during the transition process there needs to be an emphasis and education provided on communicating with physicians, self-efficacy for managing arthritis, activity/environmental modifications, medication management, coping skills, and health literacy. I have also learned several things throughout this process that will aid occupational therapists that are helping

teenagers transition to adult care. It is important to acknowledge that they have autonomy in the decision-making process when it comes to their health care, therapists need to allow the client to decide when it is time to progress through each stage in the transition process. It is also imperative that therapists provide the tools necessary to become independent with their new role, including providing the opportunity for trial and error, exploring various coping strategies, instilling the skills of time and medication management, and teaching them how to seek out reliable resources as the teens continue throughout their life span with their chronic condition.

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APPENDIX A

Communication with Physicians

When you visit your doctor, how often do you do the following (please circle **one** number for each question):

	Never	Almost never	Some-times	Fairly often	Very often	Always
1. Prepare a list of questions for your doctor	0	1	2	3	4	5
2. Ask questions about the things you want to know and things you don't understand about your treatment	0	1	2	3	4	5
3. Discuss any personal problems that may be related to your illness.....	0	1	2	3	4	5

Scoring

Score each item as the number circled. If more than one consecutive number is circled, code the lower number (less communication). If the numbers are not consecutive, do not score the item. The score is the mean of the three items. If more than one is missing, set the value of the score for the scale to missing. A higher score indicates better communication with physicians.

Characteristics

Tested on 1,130 subjects with chronic disease. N=51 for test-retest.

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
3	0-5	3.08	1.20	.73	.89

Source of Psychometric Data

Stanford Chronic Disease Self-Management Study. Psychometrics reported in: Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.24,40.

Comments

This scale was developed to see if the key behaviors we teach concerning communicating with health care providers have changed. This scale available in Spanish.

References

Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.24,40.

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4. How certain are you that you can button and unbutton 3 medium-size buttons in a row in 12 seconds?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

5. How certain are you that you can cut 2 bite-size pieces of meat with a knife and fork in 8 seconds?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

6. How certain are you that you can turn an outdoor faucet all the way on and all the way off?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

7. How certain are you that you can scratch your upper back with both your right and left hands?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

8. How certain are you that you can get in and out of the passenger side of a car without assistance from another person and without physical aids?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

9. How certain are you that you can put on a long-sleeve front-opening shirt or blouse (without buttoning) in 8 seconds?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

Self-Efficacy Other Symptoms Scale (may be combined with Pain Scale)

1. How certain are you that you can control your fatigue?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

2. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

3. How certain are you that you can do something to help yourself feel better if you are feeling blue?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

4. As compared with other people with arthritis like yours, how certain are you that you can manage arthritis pain during your daily activities?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

5. How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

6. How certain are you that you can deal with the frustration of arthritis?

very		very
uncertain	1 2 3 4 5 6 7 8 9 10	certain

Characteristics

Scale	No. of Items	Observed Range	Mean N=95 (T) N=49 (C)	Standard Deviation N=95 (T) N=49 (C)	Internal Consistency Reliability N=97	Test-Retest Reliability N=91
SE Pain	5	1-10	5.20 (T) 4.82 (C)	2.14 (T) 1.79 (C)	.75	.87
SE Function	9	1-10	7.33 (T) 6.79 (C)	2.02 (T) 2.25 (C)	.90	.85
SE Other Symptoms	6	1-10	5.56 (T) 4.92 (C)	2.16 (T) 2.06 (C)	.87	.90

Source of Psychometric Data

Stanford Arthritis Self-Management Study. Psychometrics reported in: Lorig K, Chastain RL, Ung E, Shoor S, & Holman HR: Development and evaluation of a scale to measure self-efficacy in people with arthritis. *Arthritis and Rheumatism*, 32, 1, 1989, pp. 37-44.

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the items. If more than 25% of the items are missing, do not score the scale.

Comments

The original response categories for these scales were 10-100, with "moderately certain" place midway between "very uncertain" and "very certain". We found that subjects tended to circle the phrases rather than the numbers, and there was some confusion about whether "moderate" was truly in the middle for all people, so we dropped "moderately" from the scales. Data above have been adjusted to reflect the 1-10 response categories that we use now. The Self-Efficacy Function Scale should be scored separately, but Self-Efficacy Pain and Self-Efficacy Other Symptoms may be combined.

There are 2 ways to format these items. We use the format above, because it takes up less room on the questionnaire. The other is shown on the web page.

References

Lorig K, Chastain RL, Ung E, Shoor S, & Holman HR: Development and evaluation of a scale to measure self-efficacy in people with arthritis. *Arthritis and Rheumatism*, 32, 1, 1989, pp. 37-44.

Source of Psychometric Data

Stanford Arthritis Self-Management Study participants. Unpublished.

Comments

This is the scale we use in our current studies, as it is much less burdensome for subjects than the original 3 scales with 20 total items. We have not included function items because we also use the HAQ and there is a high correlation between the SE function scale and the HAQ disability scale. There are 2 ways to format these items. We use the format above, because it takes up less room on the questionnaire. The other is shown on the web site (address below). This scale is available in Spanish.

References

Lorig K, Chastain RL, Ung E, Shoor S, & Holman HR: Development and evaluation of a scale to measure self-efficacy in people with arthritis. *Arthritis and Rheumatism*, 32, 1, 1989, pp. 37-44 (original scales).

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APPENDIX C



Health Distress

These questions are about how you feel and how things have been with you during the past month. For each question, please circle the **one** number that comes closest to the way you have been feeling.

How much time during the **past month**...

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Were you discouraged by your health problems?	0	1	2	3	4	5
2. Were you fearful about your future health?	0	1	2	3	4	5
3. Was your health a worry in your life?	0	1	2	3	4	5
4. Were you frustrated by your health problems?	0	1	2	3	4	5

Scoring

Score each item as the number circled. If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. The scale score is the mean of the four items. If more than 1 item missing, set the value of the scale to missing. Scores range from 0-5; higher score indicating more distress about health.

Characteristics

Tested on 1,130 subjects with chronic disease. N=51 for test-retest.

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
4	0-5	2.04	1.16	.87	.87

Source of Psychometric Data

Chronic Disease Self-Management Study. Psychometrics reported in: Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.25.

Comments

This is a modified version of the MOS health distress scale. We use 4 of the original 6 items, and changed the wording slightly. If possible items should be scrambled among other items using the same response categories, if possible (e.g., [Energy/Fatigue](#) scale). Because of the problems we have had using scales to measure negative emotion (e.g., depression) across cultures, we have substituted this scale. While it is not a depression or an anxiety scale, it does give us a good idea of distress caused by illness. It correlates .61 with the MOS depressive symptoms scale and .63 with the CES-D scale. Reprinted with permission, Duke University Press. This scale available in Spanish.

References

Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.25,52-53.

Stewart AL, Hays RD, & Ware JE, Health Perceptions, energy/fatigue, and health distress measures, in Stewart AL & Ware JE, *Measuring Functioning and Well-Being: The Medical Outcomes Study Approach*. Durham NC: Duke University Press, pp. 143-172.

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(650) 242-8040

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APPENDIX D



Social/Role Activities Limitations

During the **past 4 weeks**, how much... (Circle one)

	Not at all	Slightly	Moderately	Quite a bit	Almost totally
1. Has your health interfered with your normal social activities with family, friends, neighbors or groups?	0	1	2	3	4
2. Has your health interfered with your hobbies or recreational activities?	0	1	2	3	4
3. Has your health interfered with your household chores?	0	1	2	3	4
4. Has your health interfered with your errands and shopping?	0	1	2	3	4

Scoring

The score of each item is the number circled. If two consecutive numbers are circle for a single item, score the higher number (more limitation). If two non-consecutive numbers are circled, do not score the item. The score of the scale is the mean of the four items. If more than one item is missing, do not score the scale. The higher score indicates greater activities limitations.

Source of Psychometric Data

Stanford Chronic Disease Self-Management Study. Psychometrics reported in: Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.25,52-53.

Characteristics

Tested on 1,130 subjects with chronic disease. N=51 for test-retest.

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
4	0-4	1.70	1.11	.91	.68

Comments

This scale is adapted from the Medical Outcomes Study. It measures how much illness interferes with role activity. It is sensitive to change, and is a good one to use in educational studies. If you must have a short questionnaire, this is a scale to use. This scale available in Spanish. Reprinted with permission, Duke University Press.

References

Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.25,52-53.

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APPENDIX E

**Personal Health Questionnaire
Depression Scale (PHQ-8)**

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(circle one number on each line)

How often during the past 2 weeks were you bothered by...	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy.....	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

Scoring

If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. Score is the sum of the 8 items. If more than 1 item missing, set the value of the scale to missing. A score of 10 or greater is considered major depression, 20 or more is severe major depression.

Characteristics

Tested on 1165 subjects with chronic conditions.

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
8	0-24	6.63	5.52	.86	NA

Source of Psychometric Data

U.S. National Chronic Disease Self-Management Study. Study described in Ory MG, Ahn S, Jiang L, et al. National study of chronic disease self-management: six month outcome findings. Journal of Aging and Health. 2013 [in press].

Comments

This is an adaptation of the PHQ-9 scale. Since this scale is self-administered in our studies, question #9, "How often during the past 2 weeks were you bothered by thoughts that you would be better off dead, or of hurting yourself in some way?", was deleted. This scale available in Spanish.

References

Kroenke K, Strine TW, Spritzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. J Affect Disord. 2009; 114(1-3):163-73.

Razykov I, Ziegelstein RC, Whooley MA, Thombs BD. The PHQ-9 versus the PHQ-8--is item 9 useful for assessing suicide risk in coronary artery disease patients? Data from the Heart and Soul Study. J Psychosom Res. 2012; 73(3):163-168.

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smrc@selfmanagementresource.com
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APPENDIX F

Juvenile Arthritis Medical management, Self-efficacy, Symptoms limitations, and Mental health

Screen (JAMS-M Screen)

Section A: Demographic information (please select one answer for each question)

1. How older are you?
 - a. 12 and younger
 - b. 13-15
 - c. 16-18
 - d. 19-21
 - e. 22 and older
2. Are you
 - a. Female
 - b. Male
 - c. Prefer not to answer
3. What type of arthritis do you have?
 - a. JIA-Oligoarthritis (1-4 joints)
 - b. JIA-Polyarthritis (5+ joints)
 - c. JIA-Systemic
 - d. Juvenile Arthritis, Unspecified
 - e. Juvenile Rheumatoid Arthritis
 - f. Unknown Type
 - g. Other: _____
4. At what age were your diagnosed?

5. What type of doctor are you currently seeing for treatment of your arthritis?
 - a. Pediatric Rheumatologist
 - b. Rheumatologist
 - c. Pediatrician
 - d. Internal or family medicine
 - e. Don't Know
 - f. Other: _____

Section B: Communication with Physicians (please circle one number for each question)

When you visit your doctor, how often do you do the following?

1. Prepare a list of questions for your doctor

Never	Almost never	Sometimes	Fairly often	Very Often	Always
0	1	2	3	4	5
2. Ask questions about the things you want to know and things you don't understand about your treatment

Never	Almost never	Sometimes	Fairly often	Very Often	Always
0	1	2	3	4	5
3. Discuss any personal problems that may be related to your illness

Never	Almost never	Sometimes	Fairly often	Very Often	Always
0	1	2	3	4	5

(continued)

Section C: Arthritis Self-efficacy (please circle one number for each question)

How certain you are that you can do the following tasks **regularly at the present time?**

1. Decrease your pain quite a bit?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

2. Keep your arthritis from interfering with your sleep?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

3. Keep your arthritis pain from interfering with the things you want to do?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

4. Regulate your activity so as to be active without aggravating your arthritis?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

5. Keep the fatigue caused by your arthritis from interfering with the things you want to do?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

6. Do something to help yourself feel better if you are feeling blue?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

7. Deal with the frustration of arthritis?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

8. As compared with other people with arthritis like yours, how certain are you that you can manage pain during your daily activities?

very uncertain	1	2	3	4	5	6	7	8	9	10 very certain
----------------	---	---	---	---	---	---	---	---	---	-----------------

Section D: Social/Role Activity Limitations (please circle one number for each question)

During the **past 4 weeks**, how much has your health interfered with...

1. Your normal social activities with family, friends, neighbors or groups?

Not at all	Slightly	Moderately	Quite a bit	Almost totally
0	1	2	3	4

2. Your hobbies or recreational activities?

Not at all	Slightly	Moderately	Quite a bit	Almost totally
0	1	2	3	4

3. Your household chores?

Not at all	Slightly	Moderately	Quite a bit	Almost totally
0	1	2	3	4

4. Your errands and shopping?

Not at all	Slightly	Moderately	Quite a bit	Almost totally
0	1	2	3	4

(continued)

Section E: Health Distress (please circle one number for each question)

How much time during the past 4 weeks, were you...

- | | | | | | | |
|--|------------------|----------------------|------------------|------------------------|------------------|-----------------|
| 1. Discouraged by your health problems? | None
0 | A little
1 | Some
2 | A good bit
3 | Most
4 | All
5 |
| 2. Fearful about your future health? | None
0 | A little
1 | Some
2 | A good bit
3 | Most
4 | All
5 |
| 3. Frustrated by your health problems? | None
0 | A little
1 | Some
2 | A good bit
3 | Most
4 | All
5 |
| 4. Was your health a worry in your life? | None
0 | A little
1 | Some
2 | A good bit
3 | Most
4 | All
5 |

Section F: Personal Health Questionnaire (please circle one number for each question)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

- | | | | | |
|--|------------------------|--------------------------|-------------------------------------|------------------------------|
| 1. Little interest or pleasure in doing things | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 2. Feeling down, depressed, or hopeless | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 3. Trouble falling or staying asleep, or sleeping too much | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 4. Feeling tired or having little energy | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 5. Poor appetite or overeating | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | Not at all
0 | Several days
1 | More than half the days
2 | Nearly every day
3 |

(continued)

Self-Management Resource Center (n.d.b). *Communication with Physicians* [Measurement Tool]. Retrieved from https://www.selfmanagementresource.com/docs/pdfs/English_-_communication_w_physicians.pdf

Self-Management Resource Center (n.d.c). *Health Distress* [Measurement Tool]. Retrieved from https://www.selfmanagementresource.com/docs/pdfs/English_-_healthdistress.pdf

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Self-Management Resource Center (n.d.e). *Social/Role Activities Limitations* [Measurement Tool]. Retrieved from https://www.selfmanagementresource.com/docs/pdfs/English_-_social-role_activities_limitations.pdf

APPENDIX G

Staff Training Presentation



What is Occupational Therapy?

- OT is the only profession that helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations)
- OTs enable people of all ages to live life to its fullest by helping them promote health, and prevent (or live better with) injury, illness, or disability

Common interventions:

- Helping children with disabilities participate fully in school and social situations
- Helping people recovering from injury/surgery to regain skills
- Providing support for older adults experiencing physical and cognitive changes
- Helping people to adjust to a new role, environment, or diagnosis

(continued)

How is Occupational Therapy Different From Physical Therapy?



Occupational Therapy:

- OT focuses on improving a client's ability to perform activities of daily living (ADL)
- OT treats the whole person whether they are recovering from injuries or have developmental or cognitive disabilities affecting their motor skills, emotions, or behaviors
- OT not only looks at the reason a client's participation in activities has been impacted, but also the client's role and environment

Physical Therapy:

- PT focuses on improving a client's ability to perform movement of the human body
- PT treats the patient's actual impairment from a biomechanical perspective
- PT improves impairments by increasing mobility, aligning bones and joints, or lessening pain

OT Treatments

- Heat or cryotherapy to assist with pain management
- Edema control to reduce inflammation (compression garments, exercises, and splinting)
- Therapeutic activities and exercises to increase gross and fine motor control, range of motion, endurance, and strength
- Provision of custom or prefabricated orthotic devices to assist with controlling pain, maintaining functional positions of the hands, and enhancing function
- Training in the use of joint protection and energy conservation techniques, including the use of adaptive and assistive devices and modified daily routines to ensure adequate rest and to avoid overuse
- Ergonomic assessment and activity modifications in home, work, and school settings
- Training in the skills of self-managing a chronic illness including stress management, coping strategies, relaxation techniques, and nutrition

(continued)

A dark blue rectangular graphic with the word "References" in white text. In the top right corner, there are two small squares, one white and one light blue, overlapping. In the bottom left corner, there is a horizontal row of four small white squares.

References

American Occupational Therapy Association. (n.d.). What is Occupational Therapy? Retrieved July 24, 2018, from <https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx>

American Occupational Therapy Association. (2011). Occupational Therapy's Role in Managing Arthritis [Factsheet]. Retrieved July 24, 2018, from <https://www.aota.org/~media/Corporate/Files/AboutOT/Professionals/WhatIsOT/PA/Facts/Arthritis%20fact%20sheet.pdf>

St. Catherine University Online OTA. (2018, May 23). Occupational Therapy and Physical Therapy: What's the Difference? Retrieved July 24, 2018, from <https://otaonline.stkate.edu/blog/fields-occupational-therapy-and-physical-therapy-whats-difference/>

APPENDIX H

Selected blog posts



THE JA WORLD ACCORDING TO NICOLE
A Juvenile Arthritis blog with just a dash of humor

A DAY WITH JA

July is Juvenile Arthritis Awareness! Did you know that more children have arthritis than juvenile diabetes and cystic fibrosis combined? I didn't either until this morning. The difficulty with having juvenile arthritis is that many people cannot tell that you have a chronic illness or that you are sick. And when people find out that [...]

MENTAL HEALTH & WELLNESS

Did you know that rates of anxiety and depression for people with arthritis can be 2 to 10 times greater than those of the general population? If you have arthritis, then it is not that difficult for you to imagine. It's hard to go through life experiencing pain that limits your activities. It's not that [...]

[READ MORE →](#)

WHAT'S IN YOUR ARTHRITIS TOOL KIT?

When you start a DIY project at home you get out your tool kit to make sure you have all the necessary tools for the job like a screwdriver or a hammer. Well, when you go out and about with arthritis, you need your arthritis tool kit to help you! Ever since I started college, [...]

COLLEGE TIPS

Preparing for college can be overwhelming, remembering to pack all the essentials and new cool dorm room gear, but what about planning to manage your JA as you move to college? Trying to plan ahead can be difficult, but I have put together a list of some things you can do to help get you [...]

SLEEP ISSUES

If you have any type of arthritis, then I am sure you are no stranger to having issues when it comes to sleep. Whether it be trouble falling asleep, staying asleep, or trouble waking up you have probably experienced all of these at least once. One would think that if you go through your entire [...]

CLIMBING YOUR MOUNTAIN

I'm sure you're all familiar with the idea of climbing Mt. Everest and how amazing of an accomplishment that is. Well in the JA world there are plenty of "mountains" to climb. They may be physical mountains like a set of stairs or being able to play a certain sport. Or they may be more [...]

(continued)

ENERGY CONSERVATION TIPS AND TRICKS

Many of you in the chronic illness world are probably familiar with the spoon analogy. If not is essential says that you only have a certain number of spoons to use throughout the day and each activity or actions uses a certain number of spoons. However, the number of spoons available each day and the [...]

HOW TO SIGHT-SEE WITH JA

Plan ahead for the amount of walking you have to do How big is the place you are going too? Do you have to walk far away from parking or do they offer a shuttle service? For me, I like to go onto the website of the places that I want to visit to see [...]

VACATIONING WITH JA

I had the chance to travel to Florida to present a research paper that my research group and I wrote. This wasn't my first time traveling, but it was my first time traveling with my JIA as my only companion. When I am preparing for a trip I keep Murphy's Law in mind, "anything that [...]

HOW IT ALL BEGAN

If you would have told me that I would be writing a blog for others with JA (Juvenile Arthritis) and putting my story out there for others to read, I would have thought you were crazy. For those who know me, know that I typically keep my life with JIA (Juvenile Idiopathic Arthritis) private. It's [...]