Narrative Medicine Intervention for Mental Wellbeing in Juvenile Myositis and Juvenile Idiopathic Arthritis

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Abstract

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Background: Children with juvenile dermatomyositis (JDM) and juvenile idiopathic arthritis (JIA) have impaired quality of life and increased rates of anxiety and depression (15-65%), even in disease remission, when compared to healthy children. Narrative medicine is a group-based intervention that allows patients to reconstruct medical experiences through written or oral self-reflective perspectives. It has demonstrated improved patient-reported outcomes with reduced rates of depression in adults but there is limited data in pediatric rheumatology. This explorative study assesses the feasibility of a patient-targeted narrative medicine intervention and its impact on mental health burden in JDM and JIA.

Methods: We prospectively recruited patients ages 6 to with JDM and JIA for a narrative medicine intervention. Participants were divided by diagnosis and age into four narrative medicine groups, with 4-6 patients per narrative medicine session. Six sessions were held over 3 months by two trained facilitators per group. Demographic and medical information were

collected by chart review. To assess mental health, patients completed pre- and post-intervention questionnaires including Patient-Reported Outcomes Measurement Information System (PROMIS) Depression Scale, Generalized Anxiety Disorder-7 (GAD-7), Childhood Attitude Towards Illness Scale (CATIS), Patient Health Questionnaire-8 (PHQ-8), and CoVID Stress Scale (CSSQ).

Results: Twelve patients with JDM (67 % female) and nine with JIA (78% female; 4 persistent oligoarticular JIA, 3 RF-negative, 1 psoriatic JIA and 1 enthesitis-related arthritis) participated in the narrative medicine intervention. All patients participated in at least 50% of sessions. Pre-intervention, 58% of patients with JDM and 67% of patients with JIA had inactive disease, while post-intervention 70% of patients with JDM and 55% of patients with JIA had inactive disease. Wilcoxon signed-rank test revealed no statistically significant difference between pre- and post-intervention questionnaires for any of the scales. Sub-analysis of those with elevated GAD-7 and PHQ-8 pre-intervention showed trend towards improvement in anxiety ($p=0.057$) and no change for depression ($p=0.171$).

Conclusion: All patients participated in at least 50% of narrative medicine sessions, demonstrating feasibility. This exploratory study showed trend toward improved anxiety following narrative medicine session participation for those with elevated GAD7 but did not demonstrate significant changes in PHQ-8, PROMIS depression, CSSQ or CATIS scales likely due to small numbers and low level of mental health issues in those that participated in this study.

Introduction

Juvenile Dermatomyositis (JDM) and Juvenile Idiopathic Arthritis (JIA) are two rare chronic autoimmune inflammatory diseases that affect children, with JDM affecting 2 to 4 in 1 million children and JIA affecting approximately 120 in 1 million children.[1,2] Children with JDM and JIA may have an impaired quality of life and increased rates of anxiety and depression, even during disease remission, with anxiety and depression rates ranging from 15 to 65 percent and suicidal ideation rates ranging from 14 to 34 percent.[3-10] The prevalence of mood disturbance among patients with JDM and JIA is disproportionately higher than prevalence among healthy children, and is even higher than those with special health care needs or other chronic diseases such as diabetes or asthma.[3] Furthermore, recent literature suggests that individuals with childhood-onset rheumatologic disease may be at higher risk for mental health disorders than individuals with adult-onset rheumatologic disease.[10] Research shows that mental illness for pediatric patients with chronic diseases can lead to poor outcomes during childhood and affect development and risk of mental illness in adulthood. While early recognition and treatment of mental health disorders improves outcomes, there is a significant mental health care gap for youth with rheumatologic diseases. Workforce data from the American Academy of Child and Adolescent Psychiatry shows there are approximately 8,300 practicing child and adolescent psychiatrists in the US with over 15 million youth in need of this specialized care. Given this shortage and limited mental health provider availability, we must investigate alternative avenues to offer support for the aforementioned at-risk youth.[3] This study looks to investigate the feasibility of using narrative medicine as one such adjunct to standard of care medical treatment for children with rheumatic disease who are in need of mental health support.

Narrative medicine is a patient-targeted group-based intervention that allows patients to reconstruct their medical experiences through written or oral portrayals of emotions and self-reflective perspectives. It has demonstrated improved patient-reported outcomes with reduced rates of depression in adults.[11] Research suggests these group-sharing experiences improve quality of life and offer a therapeutic venue for patients with chronic diseases to support one another.[12] The mental health burden has dramatically increased during the current COVID-19 pandemic, reflecting an ongoing need for avenues to mitigate mental health burden.[13] Recognizing there is limited data to date investigating mental health improvements following narrative medicine interventions, this explorative study aims to determine if patient-targeted narrative medicine interventions improve mental health burden for individuals with JDM and JIA.

There is limited data on use of narrative medicine interventions within the rheumatologic patient population. Our prior work shows feasibility of implementation of a storytelling intervention with patients with rheumatologic diseases. The published study involved one-hour video-based narrative medicine sessions that resulted in improvement in self-reported physical health for participants following completion of the study.[14] The current study aims to build upon this prior pilot data so as to implement narrative-based intervention on a broader scale and maximize access to care for individuals with higher risk of mental health burden.

Methods

Study Design

This study aimed to understand baseline mental health burden in patients with JDM compared to patients with JIA, as well as investigate the impact a narrative medicine intervention

can have on patient-reported outcomes for patients with JDM as compared to patients with JIA. The narrative medicine intervention consisted of 3 months of bi-monthly 1-hour video-based narrative medicine sessions oriented around health-related interactions. Sessions were conducted in disease specific groups (JDM/JIA) of 4-6 patients per session, with two narrative medicine trained facilitators per session (Table 1).

Eight narrative medicine facilitators were recruited through the Northwest Narrative Medicine Collaborative. All facilitators underwent training prior to implementation of the curriculum, including introductory training on the disease course for JDM and JIA, as well as developmental expectations of participants. Facilitators were integrated into the curriculum editing process, and feedback was solicited from facilitators during and following completion of the narrative medicine sessions. Participants completed written feedback following completion of the intervention, and representative quotes of participant feedback were selected for analysis.

Age-appropriate interventions including poetry, photography, and art were used to engage participants and prompt discussions around unique medical experiences (See Appendix 1). Art supplies and writing materials were mailed to participants. A Seattle Children's psychologist through the Seattle Children's Rheumatology Clinic was made available for any patients as needed, and individuals with positive mental health screens were automatically referred for further care with the clinical psychologist.

Setting

Participants were recruited through Seattle Children's Hospital (SCH) and the SCH Juvenile Myositis Clinic of Excellence (COE). Enrolled patients participated in a bi-monthly 1-hour video-based narrative medicine session, for a total of six sessions.

Ethics Review

Ethical Approval was obtained through the Seattle Children's Hospital Institutional Review Board (STUDY00003804).

Sampling

Patients with JIA and JDM were consented through convenience sampling of patients with JDM and JIA who were seen in clinic between June 2023 and September 2023. Inclusion criteria included patients aged 6 to 21 with a diagnosis of JDM and JIA who spoke English, with non-English speakers excluded from the study due to the nature of the narrative medicine intervention being led in English.

Participants

This longitudinal cohort study prospectively recruited 12 patients with established diagnoses of JDM as well as up to 9 age-matched patients with established diagnoses of JIA. Patients with JDM from 6 to 21 years of age (case), and patients with JIA from 6 to 21 years of age (controls, age matched) were included. These patients were identified through clinic appointments as well as through referrals by attending physicians at SCH.

Measures

Participants completed RedCap surveys on demographic and medical information and questionnaires as listed below (Table 2), and reimbursements of $20 were provided for survey completion. For the PROMIS Depression Scale, a T-score of 50 represents the average depression score for the United States general population, with a score above 50 representing worse than average and a score under 50 representing better than average.[15] For the Patient Health Questionnaire-8 (PHQ-8), a score of 0 to 4 points reflects normal or minimal depression, 5 to 9 points indicates mild depression, 10 to 14 points indicates moderate depression, and 15 or more points is concerning for severe depression.[16] For the General Anxiety Disorder (GAD)-7, a

score of 5 to 9 represents mild anxiety, a score of 10 to 14 represents moderate anxiety, and a score greater than 15 represents severe anxiety.[17] For the CATIS, scores range from 13 to 65 where a higher score indicates a more positive attitude towards the condition.[18] For the COVID Student Stress Questionnaire (CSSQ), scores range from 0 to 28 where a higher score suggests higher stress in the setting of the COVID-19 pandemic.[19] Of note, no validated measures were available for these measurements in the studied population.

Statistical Analysis

Descriptive analyses were used for patient demographics. Surveys completed pre- and post-intervention were assessed for differences with a Wilcoxon signed-rank test because the data were not normally distributed. Statistical analyses were conducted using RStudio 2023.09.1, Build 494 for Windows.

Given that this is a feasibility study, process measures included participation rate and ability to complete pre- and post-participation surveys.

Results

Study Participants

Twelve patients with JDM and nine age-matched patients with JIA participated in the narrative medicine sessions (Table 3). Forty-eight percent of patients participated in 6 sessions, 19 percent of patients participated in 5 sessions, 24 percent of patients participated in 4 sessions, and 9 percent of patients participated in 3 sessions. Figures 1 and 2 demonstrate participation by age of diagnosis and age of participation. Fifty percent of approached patients with JDM and 60% of approached patients with JIA consented to participate.

Pre-Post Differences

Thirty-three percent of participants had elevated GAD-7 scores, with five participants experiencing mild anxiety and two participants experiencing moderate anxiety. Wilcoxon signed-rank test of pre- and post-participation GAD-7 scores for those with abnormal pre-participation scores indicated a non-significant large difference between before (median 7, n=7) and after (median =3, n=7) (p-value 0.0568). Thirty-three percent of participants had elevated PHQ-8 scores, with six participants experiencing mild depression and one participant experiencing moderate depression. Wilcoxon signed-rank test of pre- and post-participation PHQ-8 scores for those with abnormal pre-participation scores indicated a non-significant large difference between before (median 5.5, n=6) and after (median =4, n=6) (p-value 0.171). Table 4 demonstrates disease activity measures documented prior to and following completion of the narrative medicine intervention, and Table 5 demonstrates pre- and post-participation questionnaire responses with median scores, ranges and Wilcoxon-signed rank test results. Wilcoxon signed-rank test revealed no statistically-significant difference between pre-participation and post-participation questionnaires for GAD-7, PHQ-8, PROMIS Depression, CSSQ, and CATIS scales.

Qualitative Themes

Participants and parents submitted qualitative feedback on the impact of the intervention, with responses including “He doesn’t hate his meds anymore because he understands them better” and “I feel like I’m not alone with how I feel. [I] loved being connected with everyone.” Others shared they “learned good breathing techniques that were helpful for the IV stick on infusion day,” and “it made me re-think that there’s other people out there that are going through the same worries as me and precautions. I know I’m not alone and that there’s people out there.” When asked for feedback on areas to improve, participants and parents suggested longer time for

creative tasks before sharing as well as more frequent sessions. Some preferred to talk more about their diagnoses, while others requested less discussion about the medical experience. Several participants requested ongoing opportunities to connect with participants outside of the intervention.

Discussion

Participant attendance and engagement with each of the six narrative medicine sessions suggests feasibility of implementing a narrative-based intervention for patients with JDM and JIA. While there were no statistically significant changes in questionnaires, this is likely attributed to the small study population. Importantly, disease activity over the time course of the study showed patients with JIA had worse disease activity at the onset of the study requiring initiation of medications, whereas most patients with JDM were able to wean down on their medications, as shown in Tables 3 and 4. This is a relevant measure to consider when assessing impact on questionnaires, recognizing disease activity can play a critical role in the mental health of participants.

Compared to other studies in similar populations, rates of anxiety and depression shown in our study align with previous studies, demonstrating approximately one third of participants had elevated levels of anxiety and depression. The absence of patients with severe anxiety and depression may suggest a selection bias, recognizing those with severe mental health distress may not have energy or capability to join and participate in narrative medicine sessions. Sub-analysis of those with initially elevated levels of anxiety and depression suggest a signal towards improvement of this sub-population, suggesting future narrative medicine interventions should consider targeting those with already elevated levels of anxiety and depression.

To date, there is only one study investigating narrative medicine-based interventions within patients with pediatric rheumatologic conditions. That study implemented a single narrative medicine-based intervention and demonstrated feasibility of an intervention for pediatric rheumatologic diseases.[14] This prior study, however, included all-comers without dividing patients by disease process, all female participants including seven patients with lupus, two patients with juvenile dermatomyositis, one patient with systemic sclerosis, two patients with juvenile idiopathic arthritis, one patient with Polyarteritis Nodosa and one patient with amplified musculoskeletal pain syndrome. Additionally, the prior study had only one session involved, whereas the current study demonstrates continued adherence with a longitudinal intervention including 6 sessions.

While the current study was completed 3.5 years after the onset of the COVID-19 pandemic, elevated scores of COVID stress demonstrate ongoing distress related to COVID among patients with JIA and JDM. Despite the shift in societal expectations and masking requirements over recent years, those living with chronic diseases requiring immunosuppressive agents may continue to experience ongoing distress related to COVID. This ongoing and potentially under-recognized distress suggests a need for additional supportive resources for patients to cope with ongoing psychological distress.

Recognizing the significant barriers to access for care of mental health-related support, this narrative medicine approach offers a creative and novel adjunct intervention that can help address mental health-related concerns for patients with chronic disease. While narrative medicine does not replace professional mental health support, it may include social support missing in more traditional outpatient mental health models, thus offering a supplemental therapeutic option for patients with mental health distress. Other important adjunctive potential

therapeutic interventions include animal-assisted interventions, art, play, music and dance therapy, mindfulness, and yoga among others.[10]

As with any study, it is important to acknowledge potential challenges and barriers to study implementation and scalability. While the current study uses video-based interface of Zoom to maximize ease of access and convenience for participation, there is importantly a potential limitation of future application for individuals who do not have access to video-based technology. In the current study, families were able to join the sessions if needed over the phone without video access to maximize ability to participate. Given the intervention was Zoom-based with a risk of inattention of participants, art supplies were mailed to patients to help mitigate this potential challenge.

Given the rarity of the diseases addressed in this study, it was difficult to recruit large numbers of participants from a single site. This pilot study can serve as a basis for future multi-center collaborative research investigating the potential application of narrative medicine to support the mental health of our pediatric rheumatology patients. Additionally, while 95 percent survey completion was attained, delay in incentive payments may have resulted in decreased survey response.

Figures 1 and 2 highlight a potential selection bias for participants, recognizing that the older patients were diagnosed more remotely from participation when compared to younger patients. One potential explanation is that newly diagnosed adolescents may be less comfortable talking with others about their diagnosis when compared with adolescents who have been coping with the illness for a longer period of time. Future studies should consider investigating potential barriers to participation for newly diagnosed adolescents and integrate them in the narrative medicine intervention if possible to mitigate bias.

As with many mental health interventions, there was a risk that this study may have increased dysregulation or stress levels for participants. Participants had the ability to be connected to a psychologist through SCH, and importantly the questionnaires allowed for screening, identification and referral for treatment of at-risk individuals who may otherwise not have been identified. Recognizing the age of participants, future studies should keep in mind potentially relevant age-related adaptations of narrative-based interventions.

Conclusions

It is feasible to implement a narrative medicine intervention for pediatric patients with JIA and JDM. Future studies should target larger populations to understand the impact of narrative medicine interventions on anxiety, depression and attitude towards illness.

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Figures and Tables

Table 1: List of narrative medicine session groupings of patients with JDM and JIA.

Group	Patients	Age Range	Number of Participants
1	JDM & JIA	6-11	5
2	JIA	12-19	6
3	JDM	7-11	5
4	JDM	12-18	5

Table 2: List of instruments included in pre- and post-participation surveys of patients with JDM and JIA. PHQ-8 = Patient Health Questionnaire-8. GAD-7=Generalized Anxiety Disorder-7. CATIS=Childhood Attitude Towards Illness Scale. CSSQ=CoVID Student Stress Questionnaire

Instrument	Number of Items	Time to Complete (Minutes)	Description
PROMIS Depression Scale	28	5-10	This scale measures depression over the past seven days by measuring self-reported negative mood (sadness, guilt), views of self (self-criticism, worthlessness) and social cognition (loneliness, interpersonal alienation), and decreased positive affect and engagement (loss of interest, meaning and purpose).[15]
PHQ-8	8	1-3	This self-report measure screens for depression symptoms.[16]
GAD-7	7	1-3	This measure reflects frequency of anxiety-related symptoms over the preceding two-week period.[17]
CATIS	13	3-5	This short self-report instrument assess how favorably or unfavorably children feel about having a chronic physical condition.[18]
CSSQ	7	1-3	This scale assesses COVID-19 related distress.[19]

Table 3: Participant characteristics for patients with JDM and JIA. CCP = Cyclic Citrullinated Peptide. TNF = Tumor Necrosis Factor; PCOS = Polycystic Ovary Syndrome.

Characteristic	**JDM** (n=12) N (%)	**JIA** (n=9) N (%)	**All Participants** (n=21) N (%_
Gender* Female	8 (67)	7 (78)	15 (71)

Self-reported race[+]			
White	7 (58)	5 (56)	12 (57)
Native Hawaiian or Other Pacific Islander	1 (8)	0 (0)	1 (5)
More than one race	2 (16)	2 (22)	4 (19)
Self-reported Ethnicity[~]			
Hispanic/Latino	3 (25)	1 (11)	4 (19)
Not Hispanic/Latino	8 (67)	6 (67)	14 (67)
Other Labs			
ANA positive	N/A	6 (67)	N/A
ANA negative	N/A	3 (33)	N/A
HLA-B27 positive	N/A	0 (0)	N/A
HLA-B27 negative	N/A	8 (89)	N/A
HLA-B27 equivocal	N/A	1 (11)	N/A
Rheumatoid Factor positive	N/A	0 (0)	N/A
Rheumatoid Factor negative	N/A	9 (100)	N/A
CCP positive	N/A	0 (0)	N/A
CCP negative	N/A	9 (100)	N/A
Myositis Antibody Panel			
Negative	7 (56)	N/A	N/A
P155/140	2 (16)	N/A	N/A
Mi2	3 (24)	N/A	N/A
MJ	1 (8)	N/A	N/A
Disease-Related Complications			
Cataracts	1 (8)	0 (0)	1 (5)
Calcinosis	1 (8)	0 (0)	1 (5)
Pharyngeal weakness	1 (8)	0 (0)	1 (5)
Lipodystrophy	1 (8)	0 (0)	1 (5)
Boutonnieres deformity	0 (0)	1 (11)	1 (5)
Leg-length discrepancy	0 (0)	1 (11)	1 (5)
TNF-induced psoriasis	0 (0)	1 (11)	1 (5)
Comorbidities			
Asthma/Reactive Airway Disease	1 (8)	1 (11)	2 (10)
Congenital Hypothyroidism	1 (8)	0 (0)	1 (5)
Hypersensitivity vasculitis	0 (0)	1 (11)	1 (5)
Pain amplification	0 (0)	1 (11)	1 (5)
PCOS	0 (0)	1 (11)	1 (5)
Recurrent Urinary Tract Infections	1 (8)	0 (0)	1 (5)
Medication changes between surveys	9 (75)	2 (22)	11 (52)
No change	1 (8)	1 (11)	2 (10)
Steroid wean	1 (8)	0 (0)	1 (5)
Plaquenil wean	0 (0)	1 (11)	1 (5)
Plaquenil started	1 (8)	0 (0)	1 (5)
Abatacept started	0 (0)	1 (11)	1 (5)
Adalimumab started	0 (0)	1 (11)	1 (5)

Etanercept started	0 (0)	1 (11)	1 (5)
Golimumab started	0 (0)	1 (11)	1 (5)
Leflunomide increased	0 (0)	1 (11)	1 (5)
Tocilizumab increased			

* 1 preferred not to answer and 1 did not respond; [+] 1 was not sure of their race, 1 preferred not to answer, and 2 did not respond; [~]1 was not sure of their ethnicity, 1 preferred not to answer, and 1 did not respond.

Table 4: Pre-participation and post-participation disease measures of physician-reported global and myositis measures for patients with juvenile idiopathic arthritis and juvenile dermatomyositis. JDM = Juvenile Dermatomyositis. JIA = Juvenile Idiopathic Arthritis. MMT8 = Manual Muscle Testing-8. CMAS = Childhood Myositis Assessment Scale. CDASI = Cutaneous Dermatomyositis Disease Area and Severity Index.

Measure	Pre-Participation N (%)			Post-Participation N (%)		
	JDM	JIA	All	JDM	JIA	All
Physician-Reported Global	2 (16)	1 (11)	3 (14)	4 (33)	3 (33)	7 (33)
Not documented	6 (50)	3 (33)	9 (43)	5 (42)	4 (44)	9 (43)
0/10	3 (24)	1 (11)	4 (19)	2 (16)	1 (11)	3 (14)
1/10	1 (8)	0 (0)	1 (5)	1 (8)	0 (0)	1 (5)
2/10	0 (0)	3 (33)	3 (14)	0 (0)	1 (11)	1 (5)
3/10	0 (0)	1 (11)	1 (5)	0 (0)	0 (0)	0 (0)
4/10						
MMT8						
Not documented	2 (16)			3 (24)		
144	1 (8)			0 (0)		
145	0 (0)			1 (8)		
147	1 (8)			1 (8)		
149	4 (33)			1 (8)		
150	4 (33)			6 (50)		
CMAS						
Not documented	4 (33)			4 (33)		
42	1 (8)			0 (0)		
44	0 (0)			1 (8)		
47	1 (8)			1 (8)		
48	0 (0)			1 (8)		
50	1 (8)			0 (0)		
51	0 (0)			1 (8)		
52	5 (42)			4 (33)		
CDASI Activity						
Not documented	2 (16)			4 (33)		
0/96	6 (50)			5 (42)		
1/96	4 (33)			1 (8)		
2/96	0 (0)			1 (8)		

3/96	0 (0)		1 (8)
CDASI Damage			
Not documented	2 (16)		4 (33)
0/32	9 (75)		5 (42)
1/32	1 (8)		2 (16)
3/32	0 (0)		1 (8)

Table 5: Wilcoxon signed-rank test of pre-participation and post-participation questionnaires for patients with juvenile idiopathic arthritis and juvenile dermatomyositis. JDM = Juvenile Dermatomyositis. JIA = Juvenile Idiopathic Arthritis. PHQ-8 = Patient Health Questionnaire-8. GAD-7=Generalized Anxiety Disorder-7. CATIS=Childhood Attitude Towards Illness Scale. CSSQ=CoVID Student Stress Questionnaire.

Measure	Pre-Participation median (range)			Post-Participation median (range)			P-Value		
	JDM	JIA	All	JDM	JIA	All	JDM	JIA	All
GAD7	2 (0-10)	3.5 (0-13)	3 (0-13)	1.5 (0-5)	2.5 (0-13)	2 (0-13)	0.219	0.203	0.070
PHQ-8	2.5 (0-7)	3.5 (0-13)	3 (0-13)	1 (0-10)	2 (0-9)	2 (0-10)	0.833	0.394	0.317
PROMIS Depression	45.9 (35.9-57.6)	48.1 (35.9-62.5)	45.9 (35.9, 62.5)	45.9 (35.9-57.8)	48.1 (35.9-64)	48.1 (35.9, 64)	0.695	0.575	0.948
CATIS	45.5 (36-58)	39.5 (24-55)	42 (24, 58)	45.5 (31-59)	42 (31-52)	43.5 (31, 59)	0.637	0.674	0.950
CSSQ	2.5 (1-16)	4 (0-8)	3 (0, 16)	3 (0-10)	6 (0-14)	4 (0, 14)	0.964	0.090	0.314

Figure 1: Participation by age of diagnosis and age of participation for patients with Juvenile Dermatomyositis as per self-report.

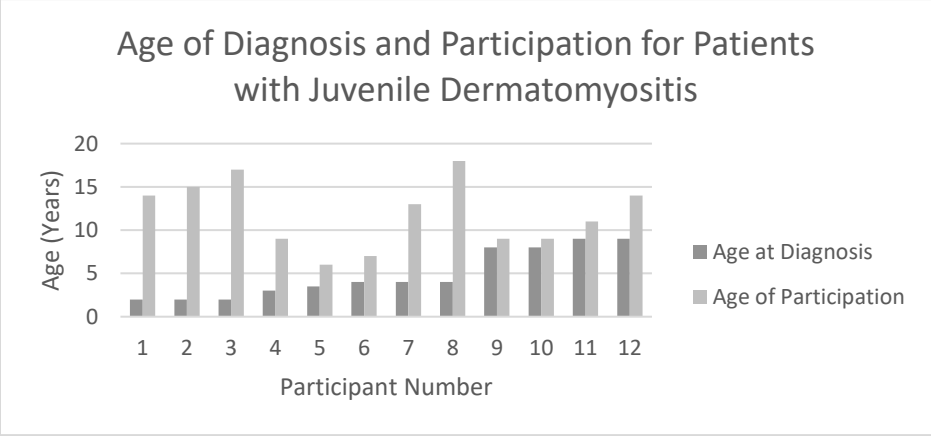
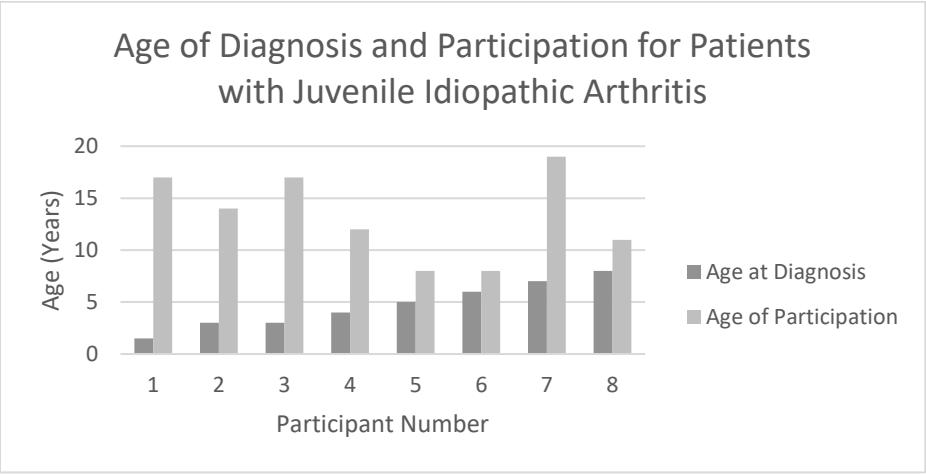


Figure 2: Participation by age of diagnosis and age of participation for patients with Juvenile Idiopathic Arthritis as per self-report.



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