

# Mental health in paediatric and adult myositis-related diseases: current state of research, interventions, and future steps from the MIHRA Psychological Impact Scientific Working Group

A. Lanis<sup>1</sup>, H. Alexanderson<sup>2</sup>, K. Ardalán<sup>3</sup>, S. Edison<sup>4</sup>, C.D. Graham<sup>5</sup>, I. de Groot<sup>6</sup>, L. Gupta<sup>7,8</sup>, S. Kim<sup>9</sup>, A.M. Knight<sup>10,11</sup>, L. Kobert<sup>12</sup>, P. Livermore<sup>13</sup>, C. Lood<sup>14</sup>, C. Pilkington<sup>13</sup>, M. Regardt<sup>15,16</sup>, T.B. Rubinstein<sup>17,18</sup>, S. Shenoï<sup>1</sup>, L. Turnier<sup>19</sup>, N.B.M. Voet<sup>20,21</sup>, D.M. Wahezi<sup>17,18</sup>, L.A. Saketkoo<sup>22-25</sup>

*Affiliations: see page 420.*

*Aviya Lanis, MD*

*Helene Alexanderson, PhD, RPT*

*Kaveh Ardalán, MD, MS*

*Suzanne Edison, MA, MFA*

*Christopher D. Graham, PhD*

*Ingrid de Groot*

*Latika Gupta, MD, MRCP, DM*

*Susan Kim, MD, MMSc*

*Andrea M. Knight, MD, MSCE*

*Linda Kobert, MSN*

*Polly Livermore, PhD, MS*

*Christian Lood, PhD*

*Clarissa Pilkington, MBBS*

*Malin Regardt, PhD*

*Tamar B. Rubinstein, MD, MS*

*Susan Shenoï, MBBS, MS, RhMSUS*

*Luke Turnier, PsyD*

*Nicole B.M. Voet, MD, PhD*

*Dawn M. Wahezi, MD, MS*

*Lesley Ann Saketkoo, MD, MPH*

*Please address correspondence to:*

*Aviya Lanis*

*Seattle Children's Hospital,*

*9416 1st Avenue NE,*

*98115 Seattle, WA, USA.*

*E-mail: aviya.lanis@seattlechildrens.org*

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### ABSTRACT

*Psychological and emotional well-being are critical aspects of overall health for individuals with chronic rheumatologic conditions. Mental health-related literature, however, predominantly focuses on systemic lupus erythematosus or rheumatoid arthritis, with limited emphasis on idiopathic inflammatory myopathies (IIMs). High proportions of those with juvenile myositis report psychological distress at levels warranting mental health referral. Adults with dermatomyositis diagnosed with depression or anxiety do not receive adequate mental health care. Mental health symptoms in those with IIMs are associated with worse health-related quality of life, medication adherence, and disease outcomes. Despite demonstrated high rates of mental health burden, access to mental health care remains severely lacking.*

*Data related to mental health burden is limited by small sample size, limited generalisability, variable methods of assessment, and inconsistent diagnosis codes to define mental health conditions. Additional research is needed to validate current screening tools in myositis populations. Other relevant measurable factors include disease severity, non-health- and health-related trauma exposure, loneliness, isolation, loss of control, sleep difficulties, fatigue, pain, self-esteem, body image, sexual health, and health inequities. Studies are needed investigating the efficacy of therapeutic and pharmacologic interventions among patients with myositis*

*who experience depression and anxiety. Currently, knowledge and resources are limited around mental health burden and potential intervention for those living with IIMs. The Myositis International Health & Research Collaborative Alliance (MIHRA) Psychological Impact Scientific Working Group offers a preliminary road map to characterise and prioritise the work ahead to understand baseline mental health burden and compare avenues for intervention.*

### The current state of affairs: understanding emotional challenges for adults and children with myositis

Psychological and emotional well-being are critical aspects of overall health for individuals with chronic rheumatologic conditions. In a post-pandemic era, mental health burden has increased, amplifying a long-standing shortage of behavioural health providers (1-4). Mental health-related concerns have been shown to impact Health-Related Quality of Life (HRQoL), educational and occupational attainment, treatment adherence, healthcare utilisation and transition among those with paediatric and adult rheumatologic conditions, although literature in myositis is still lacking (5). In 2020, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) established a prioritised research agenda to address gaps in knowledge related to the mental health of youth with rheumatologic disease (6). The international myositis research community has established a similar

dedication to understanding mental health burden among those with rheumatologic conditions, with a particular focus on representing individuals' perceptions of the disease's effect on their daily lives (7). The Myositis International Health & Research Collaborative Alliance (MIHRA) Psychological Impact Scientific Working Group presents here a scoping review of the current knowledge of mental health burden in IIMs and offers a preliminary road map to help characterise and prioritise the work ahead.

Depression and anxiety are common among adults with chronic rheumatologic conditions. They have a nearly two-fold higher prevalence of anxiety disorders and a higher likelihood of having multiple psychiatric disorders (odds ratio (OR)=2.7, 95% confidence interval (CI)=1.5-5.0) than general populations (8). Mental health-related literature, however, predominantly focuses on individuals with systemic lupus erythematosus (SLE) or rheumatoid arthritis (RA), with limited emphasis on those with myositis. A systematic review of HRQoL measures demonstrated significantly lower HRQoL in those with idiopathic inflammatory myopathies (IIMs), and a significant correlation between HRQoL and depression and anxiety (9). Another cross-sectional study demonstrated over 40% of adults with dermatomyositis (DM) met the criteria for depression or anxiety, with one-third of those individuals not receiving mental health care (10). Another study observed that one-fifth of those with inclusion body myositis (IBM) presented with significant levels of anxiety or depression (11). Adults with IIMs in 48 countries similarly conveyed high cognitive impact, difficulty sleeping, and emotional distress (12). One study comparing individuals with IIM to those with non-IIM autoimmune inflammatory rheumatic diseases (AIRDs), non-rheumatic autoimmune inflammatory diseases (NRAIDs) and healthy controls, demonstrated higher rates of mental health disorders among those with IIM (33.4% IIM vs. 28.2% non-IIM AIRDs vs. 28.4% NRAIDs vs. 17.9% controls,  $p < 0.001$ ) (13).

Children in North America, South

America, Europe, and Asia with chronic rheumatologic conditions have higher rates of mental health-related concerns than healthy peers, with depression and anxiety rates from 15 to 65% and suicidal ideation rates from 15 to 34% (14-16). Recent studies distinguish individuals with childhood-onset rheumatologic disease as being at higher risk for mental health disorders than those with adult-onset disease (16). Mental health symptoms in these children are associated with worse HRQoL, poor medication adherence, and potentially worse disease outcomes (17-21). Disease severity has also been associated with decreased academic achievement among children diagnosed with childhood onset chronic rheumatic diseases (22). The interaction between disease course, school attendance, neuropsychological challenges, and mental health burden have not been fully explored among children with myositis. Current literature largely reflects juvenile idiopathic arthritis (JIA) and SLE, with limited research investigating mental health burden related to juvenile myositis (6, 21). Despite this, the evidence to date regarding juvenile myositis indicates that these youth may be particularly impacted by poor mental health. Greater than 40% of those with juvenile myositis in a study from the United Kingdom reported sufficient psychological distress to warrant referral to a mental health specialist (23). A subsequent multicentre North American study conducted during the COVID-19 pandemic found that nearly 70% of children with juvenile myositis have positive mental health screening results also requiring further evaluation of potential mental health comorbidities (24). Further, even those with well-controlled juvenile dermatomyositis (JDM) had significantly worse psychosocial functioning scores compared to healthy counterparts (25). A qualitative study of 45 parents of children and young adults ranging in age from 6 to 21 years with juvenile myositis identified significant concerns around anxiety, uncertainty, and emotional distress for their children, with negative impacts on siblings and family relations (26). This study highlighted the differences in age-based experience

of distress, recognising a 6-year old's anxiety crisis may include enuresis and nightmares while a 17-year old's diminished self-esteem may be expressed verbally or through self-isolation.

The COVID-19 pandemic has played a crucial role in amplifying the already demonstrated mental health epidemic, particularly impacting the myositis community (27, 28). One study in Hungary found that patients with myositis had an increased risk of COVID-19 infection compared to national infection rates (28). Another study out of Israel raised concern for increased incidence and more severe presentation of IIMs during the COVID-19 pandemic when compared to pre-pandemic (29). Several studies suggested a potential correlation between onset or flares of IIM with COVID-19 infection and/or vaccination (30-32). Literature demonstrates a detrimental effect of the pandemic on continuity of care for many patients with IIM, raising concern for risk of downstream effects on disease outcomes for patients as well (33, 34). In addition, the pandemic prevented indoor exercise and physical activity at gyms for patients with myositis, likely further contributing to worse mental health outcomes for patients recognising the therapeutic nature of exercise both physically and mentally. Emerging evidence has confirmed a similar negative impact of the pandemic on mental health for adult and paediatric patients with IIM, raising concern around potential long-term effects of isolation and psychosocial stressors (35, 36).

Despite demonstrated high rates of mental health burden, access to mental health care remains severely lacking. The American Academy of Child and Adolescent Psychiatry report approximately 8,300 practicing child and adolescent psychiatrists in the United States (US), while over 15 million youths are in need of one (37). Increasing workforce shortages and barriers to accessible quality mental healthcare are escalating this burden (38). The Child and Adolescent Mental Health in Europe project mirrors these gaps in provider education and available preventative services for child mental health across 15 countries (39). Echoing this, one-

**Table I.** More commonly used instruments measuring anxiety and depression among paediatric and adult patients with rheumatologic conditions.

Instrument	Number of items	Target age (years)	Time to complete (minutes)	Rheumatologic conditions Studied with Measure <sup>2</sup>
<b>Anxiety measures<sup>21, 125</sup></b>				
Beck Anxiety Inventory	21	18 and older	5-10	Fibromyalgia, <sup>126</sup> JIA, <sup>127</sup> OA, <sup>128</sup> RA, SLE, SSc, <sup>129</sup> Myositis <sup>130</sup>
Beck Youth Inventory (BYI)-Anxiety Inventory	20	7-18	5	JIA <sup>131</sup>
Generalized Anxiety Disorder-7 (GAD-7) <sup>132</sup>	7	14 and older	<3	AS, RA, <sup>133</sup> Myositis <sup>81</sup>
Hamilton Anxiety Scale (HAM-A) <sup>134</sup>	14	18 and older	10-15	RA, <sup>135</sup> CTD <sup>136</sup>
Hospital Anxiety and Depression Scale – Anxiety (HADS-A)	7	16-65	<5	SS, <sup>137</sup> AS, <sup>138</sup> Arthritis, <sup>139-141</sup> SLE, <sup>142</sup> Myositis <sup>143</sup>
Impact of Rheumatic Diseases on General Health and Lifestyle (IRGL) Anxiety Scale	10	18 and older	5	RA, <sup>144</sup> AS, Psoriatic Arthritis, OA <sup>145</sup>
Patient-Reported Outcomes Measurement Information System (PROMIS) Anxiety Scale <sup>146</sup>	29 (computer adaptive test) or 4-8 (4 short forms)	8-17	5	Juvenile fibromyalgia, <sup>147</sup> cSLE, <sup>125</sup> Myositis <sup>148</sup>
Paediatric Symptom Checklist-17 (PSC-17)	17	4-17	<5	Myositis <sup>93</sup>
Screen for Childhood-Related Emotional Disorders (SCARED)	41	8-18	10	JIA, <sup>149</sup> cSLE, pMCTD, <sup>150</sup> Myositis <sup>24</sup>
State-Trait Anxiety Inventory for children (STAI-C)	40	9-12	10	JIA, <sup>149</sup> cSLE <sup>123</sup>
State-Trait Anxiety Inventory (STAI) <sup>151</sup>	6 (short form) or 40 (long form)	13 and older	10	RA, <sup>152</sup> SLE, <sup>153</sup> Fibromyalgia, SSc <sup>154, 155</sup>
<b>Depressive symptom measures</b>				
Beck Depression Inventory (BDI)	21	13 and older	10	JIA, <sup>129</sup> Myositis <sup>156</sup>
Centre for Epidemiological Studies Depression Scale for Children (CES-DC)	20	6-17	5	JIA <sup>129</sup>
Children's Depression Inventory (CDI)	27 (long form) or 10 (short form)	7-17	5-15	cSLE, <sup>21</sup> FMF, <sup>157</sup> JIA <sup>129</sup>
Hamilton Depression Rating Scale (HAM-D)	21	18 and older	15-20	RA, <sup>158</sup> SLE <sup>159</sup>
IRGL Depressed Mood Scale	6	18 and older	<5	RA, <sup>158</sup> AS, Psoriatic Arthritis, OA <sup>144</sup>
Montgomery-Asberg Depression Rating Scale (MADRS)	10	18 and older	5	SLE, RA, SSc, <sup>152</sup> Bechets <sup>160</sup>
Mood Disorder Questionnaire (MDQ)	15	12 and older	5	RA <sup>161</sup>
Mood and Feeling Questionnaire for children (MFQc)	13 (short form) or 33 (long form)	6-17	5-10	JIA <sup>129</sup>
Patient Health Questionnaire-9 (PHQ-9)	9	12 and older	5	cSLE, pMCTD, <sup>149</sup> RA, Psoriatic Arthritis, AS, SLE, SSc, Vasculitis, SS, Myositis <sup>162</sup>
PROMIS Depression Scale	12 (computer adaptive test) or 4-8 (short form)	8-17	5	Juvenile fibromyalgia, <sup>147</sup> cSLE, <sup>21</sup> Myositis <sup>148</sup>
<b>Anxiety and depressive symptom combined measures</b>				
Child Behavioural Checklist (CBCL)	113	6-18	10	JIA <sup>129</sup>
Depression, Anxiety and Stress Scale-21 (DASS21)	21	18 and older	5	OA, RA, SLE, <sup>163</sup> Myositis <sup>164</sup>

Myositis represents both paediatric and adult inflammatory myopathies.

JIA: juvenile idiopathic arthritis; RA: rheumatoid arthritis; SLE: systemic lupus erythematosus; SSc: systemic sclerosis; cSLE: childhood SLE; pMCTD: paediatric mixed connective tissue disease; AS: ankylosing spondylitis; CTD: connective tissue disease; SS: Sjögren's syndrome; OA: osteoarthritis; FMF: familial Mediterranean fever.

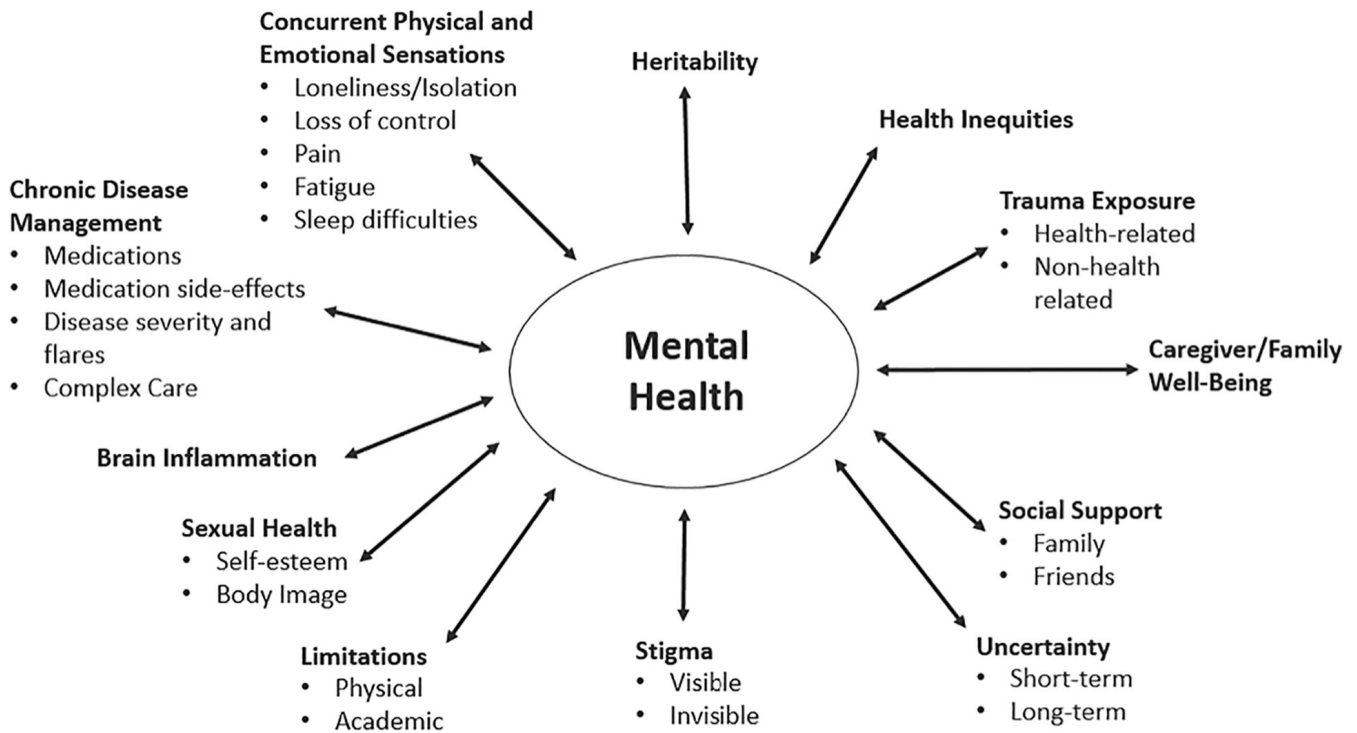
third of 100 CARRA centres, and nearly half of 15 UK centres, reported having no affiliated social worker or psychologist, and demonstrated barriers to mental health interventions included limited resources, lack of diagnostic and referral protocols, as well as patient-borne cost and time burden (40, 41). A North American multicentre mental health screening study further found that 75% of those with juvenile myositis referred for evaluation of positive mental health screening results did not access timely

follow-up (42). This paper highlights the literature currently available addressing mental health concerns and access to care among children and adults with IIM, with more references currently available in the paediatric literature as compared to the adult side.

### How do we currently measure psychosocial and mental health-related distress?

Data related to mental health burden is limited by small sample sizes with

limited generalisability as well as varied methods for measurement including symptom screeners, and diagnosis codes to define mental health conditions (16). Though under-utilised and some under-validated, more commonly used screening tools and symptom measures for anxiety and depression in adult and paediatric rheumatologic population are characterised in Table I. This summary table excludes measures typically used to evaluate features specific to panic disorder, obsessive-



**Fig. 1.** Conceptual model of measurable and relevant psychological factors.

compulsive disorder, and posttraumatic stress disorder, focusing on measures that provide broad inclusion of general anxiety symptoms. Use of these tools for individuals with myositis in clinical and research settings is limited in the current literature.

There are various conceptually relevant comorbidities to consider when measuring mental health burden. Sleep difficulties and disorders, for example, are associated with a wide variety of rheumatologic conditions and play an important role in mental health (43). Loneliness has clear associations with biophysical-based survival outcomes comparable to cigarette smoking across the general population (44). Loneliness and isolation are prevalent among individuals with rheumatic disease and are related to lack of social support, stigmatisation and invalidation. Self-esteem and body image, challenged by disease-related body changes may also drive mental health burden among those with rheumatologic diseases (45-47). Sexual health is another important factor that can influence psychosocial health among people who live with rheumatologic diseases. Studies demonstrate increased sexual concerns among

those with rheumatoid arthritis, systemic sclerosis and myositis, with limited data, as of yet, investigating sexual health among individuals with myositis (48-50). Recognising the impact of loss of control and potential health-related trauma, future studies are needed to investigate the role of these factors (51). Health inequities and exposure to trauma are additional factors of interest that interplay with mental health outcomes for individuals with rheumatologic diseases. But there are not yet studies among those with myositis (52, 53). Figure 1 identifies a conceptual model of relevant factors to incorporate when evaluating mental health impact for those living with myositis.

#### **What do we know about ways to intervene?**

Early identification and treatment of mental health difficulties improves outcomes. Varied psychological interventions for children with chronic illness demonstrate consistent improvement in clinical outcomes, particularly when symptoms are recognised and managed early (54, 55). Early identification of depression in adults decreases the risk for major depression and suicide and

improves social function and productivity (56, 58).

Beyond the early identification of mental health, person-centred communication and culture healthcare interactions, can transform the psychological profile related to living with a chronic health condition. The global adoption of shared decision-making and trauma-informed/shame-sensitive communication is increasingly becoming the standard of care (59-67). These are non-threatening and power-equalising approaches predicated on unwavering respect, active listening and choice. These approaches may benefit the well-being of all stakeholders regardless of mental health or trauma history. Positive Health Philosophy echoes these principles and strives to develop an antidote for deep-rooted operative social values referred to as 'ableism'. Ableism unconsciously correlates worth with ability versus disability, health versus illness and assistive modifications/services as being concessionary versus universally enabling (68-70). Person-positive philosophies safeguard inter-communication fluency, personalisation and sustainability of holistic health strategies, and recognises traditional medical tendencies of

**Table II.** Potential methods to address mental health burden among those living with myositis.

Potential resources
<b>Psychological interventions</b>
ACT*
CBT* and Cognitive behavioural self-help*
Disease education and psychoeducation
Talk and family therapy*
<b>Pharmacologic interventions</b>
Biologics
SNRIs*
SSRIs*
<b>Additional therapeutic interventions</b>
Animal-assisted intervention*
Art, play, music and dance therapy*
Embodiment practices
Mindfulness*
Narrative medicine and poetry
Occupational balance*
Patient associations
Physical activity and exercise*
Resistance strength building*
Singing, humming, chanting
Spirituality
Yoga*

\*Supported literature for intervention among those with IIM.

\*Supported literature for intervention among those with mental health burden.

ACT: Acceptance and Commitment Therapy; CBT: Cognitive Behavioural Therapy; SSRI: Selective serotonin reuptake inhibitors; SNRI: Serotonin and noradrenaline reuptake inhibitors.

‘deficit-’ and ‘fixing-’ directed language as potentially objectifying and eroding patient-perceived self-worth.

Promising interventions, such as Acceptance and Commitment Therapy (ACT) and Cognitive Behavioral Therapy (CBT) are receiving serious research attention in muscle disorders including myositis. ACT is a newer psychological therapy that includes aspects of mindfulness, goal-setting, and perspective-taking techniques to facilitate the development of psychological flexibility, which can be defined as: “the capacity to persist or to change behaviour in a way that includes conscious and open contact with thoughts and feelings, appreciates what the situation affords, and serves one’s goals and values” (71). On the basis of an observational study that showed significant correlations between psychological flexibility and well-being and mood in muscle disorders, including myositis, a

**Table III.** Roadmap of future work in understanding and addressing mental health for individuals with myositis.

Future avenues to understand mental health in myositis-related disorders
<i>Understanding the problem</i>
<ul style="list-style-type: none"> <li>• Characterise relevant baseline psychosocial factors (Fig. 1)</li> <li>• Validate mental health measures in myositis populations (Table I) Investigate biophysical measures in mental health including biomarkers and functional magnetic resonance imaging</li> <li>• Investigate systemic, iatrogenic environmental and personal factors contributing toward resilience and holistic well-being</li> <li>• Understand geographic disparities in mental health burden among individuals with myositis</li> <li>• Characterise the impact of living with IIMs in early life with satisfaction of foundational education</li> <li>• Characterise the impact of IIMs on occupational balance</li> </ul>
<i>Investigating solutions and establishing next steps</i>
<ul style="list-style-type: none"> <li>• Investigate and develop feasible interventions and models to maximize access to mental health care including: <ul style="list-style-type: none"> <li>◦ Integration of mental health support strategies within clinics</li> <li>◦ Telehealth mental health services implementation</li> <li>◦ Training myositis specialists around identifying mental health burden and activating psychosocial supports</li> </ul> </li> <li>• Randomised control trials investigating outcomes of non-pharmacological mental health interventions (Table II)</li> <li>• Identify and assess resilience and holistic well-being fortification strategies</li> <li>• Assess and improve resources available during transition from paediatric to adult care</li> <li>• Establish models of wrap-around services for significant others, parents, teachers, family, and siblings of individuals with myositis</li> </ul>

randomised controlled trial of ACT in adults with myopathies including IBM, was completed (72). This fully powered trial demonstrated efficacy for improving distress and HRQoL, with moderate improvements seen in both of these outcomes following only a brief intervention (73). In other myopathies there is evidence that CBT alone or combined with exercise can be helpful for improving fatigue and associated outcomes in those with severe fatigue (74). Studies in cSLE tailoring CBT approaches for adolescents and young adults with cSLE through The Treatment and Education Approach for Childhood-onset Lupus suggest potential avenues to adapt CBT for myositis as well (75).

Physical activity and exercise interventions in IIMs are associated with reduced muscle inflammation and increased repair (76–80). The Mental health domain was significantly improved after 12 weeks of intensive aerobic and muscle endurance exercise in a group of patients with myositis (81). Similarly, 24 weeks of functional strength and balance training in patients with myositis significantly reduced depression and anxiety compared to a non-exercising control group (80). However, positive studies in RA prompt considerations to investigate physical activity effects

more deeply on mental health and psychological well-being in IIMs (82). A systematic data review of venerable yogic practices in neuromuscular and other diseases extrapolated that yogic interventions appear to be safe and probably beneficial for chronic pain and mental health burden in those with myositis (83). Similarly, it is possible that singing, humming, and chanting may improve important myositis-related manifestations such as xerostomia, diaphragmatic weakness, pulmonary function, and even balance. One study in inflammatory arthritis has shown a correlation between mental health and occupational balance, indicating that mental health is affected by the need to manage everyday activities while living with a chronic disease (84). The importance of occupational balance is also described in young adults with mental illness who experienced being under-occupied with too little to do (85). However, the majority of research into self-sounding assesses psychological impact across health conditions and has yet to be evaluated for IIM. Positive health philosophy has created shifts in focus across disciplines and specialties towards enhancing capability in treatment and improving health and resilience through first and fore-

most seeing patients as people with full lives coupled with shared decision-making (SDM). This approach identifies patient priorities and preferences which then inform opportunities for people to be and do things they value and find personally meaningful in the context of also living with a serious health condition (86-90).

First-line pharmacologic interventions for individuals with rheumatologic conditions with moderate to severe depression include selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine, paroxetine, fluvoxamine, citalopram and sertraline. Serotonin and noradrenaline reuptake inhibitors (SNRIs) are also considered for treatment. Interestingly, recognising that pro-inflammatory cytokines may promote depression, biologics that block pro-inflammatory cytokines, including infliximab, etanercept, or adalimumab, are potential avenues for treatment of depression in those with rheumatologic conditions as well (90).

#### **Are mental health resources, accessibility and integration feasible goals?**

Models of mental health services integration with physician education have been effective among those with chronic diseases such as diabetes and cystic fibrosis, and potentially predict similar success in IIMs (91, 92). Roadmaps for integrating behavioural health care within paediatric rheumatology and juvenile myositis clinics demonstrate feasibility and provide guidance for replication (93, 94). Integrated behavioural health services for adults with neuromuscular conditions are shown to reduce hospital length of stay, improve adherence, decrease emergency department visits, reduce mental health symptoms, provide pain relief, and improve HRQoL, as well as reduce emergency behavioural health spending by 19% and offset medical costs by 20% (86).

While integration of mental health services within paediatric rheumatology clinics may be ideal, given the ongoing shortage of mental health providers it is important to consider additional avenues of support. Since the onset of the COVID-19 pandemic, telehealth has been of growing utility to expand access

to psychological care (95). In addition to allowing families increased access to mental health care when impeded by location or financial burden, children and young adults reported a positive therapeutic alliance with mental health providers who utilised telehealth (96). This growing field deserves further understanding of potential utility, efficacy and barriers for implementation.

The American Board of Paediatrics (ABP) has established ongoing support to promote longitudinal partnerships between paediatric subspecialists and behavioural health providers within integrated ambulatory and inpatient settings, including an ABP Roadmap initiative to this effect (97). Parents of children with juvenile myositis identify paediatric rheumatologists as facilitators of emotional health care, recognising that those with juvenile myositis trust, respect and disclose emotional distress with their providers (26). Recent efforts include education of paediatric rheumatologists to help identify and treat individuals with mental health burden (14, 98, 99).

#### **Future steps for research and clinical care investigations**

The established literature delineates areas of strong need in both clinical care and research. The MIHRA Psychological Impact Scientific Working Group offers a preliminary road map to help characterise and prioritise the work ahead (Table III).

Understanding baseline mental health status and contributing factors is a key first step to moving forward with establishing relevant interventions. Guidance on which instruments to use, and whether new instruments require development is an important question. Recognising potential for day-to-day variability in self-reported screening outcomes, future studies should strive to outline preferred screening administration intervals (100). One study showed that forty-three surveyed individuals with juvenile myositis and their caregivers self-reported receiving a clinical diagnosis of depression (39%), or anxiety (35%), while an additional 18% and 27% without formal diagnoses reported depression and anxiety symptoms, respectively (24, 101). This study was limited by

individuals' self-reported mental health without performance assessment using validated tools. These findings support a role for systematic measurement of psychosocial health in juvenile myositis using validated tools. It also raises the question of potential utility of non-survey assessment of mental health burden among patients.

While there is a growing understanding of the prevalence and incidence of mental health burden among individuals with rheumatologic conditions, more research is needed to understand whether symptoms arise as part of the inflammatory disease itself, as a reaction to the disease burden, or as a coincidental concomitant entity (6). Recent studies have shown a causal association between interleukin (IL) 6 signalling and depression, with other studies suggesting CRP concentration to be associated with negative affect, pain and inflammation (102, 103). Burgeoning literature demonstrates utility of biomarkers for psychiatric diagnosis, prognosis and treatment, with additional literature investigating the role of pro-inflammatory cytokines on psychotherapy for depression (104-106). Interestingly, treatment with antidepressants for those with depression has been associated with reductions in peripheral cytokine levels, and importantly, psychotherapy alone has been similarly shown to reduce serum cytokine levels (105, 106). The Lupus Erythematosus and Dermatomyositis Stress and Cardiovascular Health (LEADS-CV) study is currently ongoing and aims to evaluate relationships of stress with inflammation and cardiovascular health in cSLE and JDM patients, with findings forthcoming (107). These efforts suggest the potential overlap in underlying pathology between myositis and mental health disorders, opening opportunities for potential future research exploration. This is an avenue of increasing importance in the setting of subjective and imprecise patient-reported measures of mental health currently available that are complicated by patient-based inter-rater, cultural and linguistic differences (108).

Another crucial piece in understanding the neuro-inflammatory role in mental health burden among those with

myositis may be the characterisation of impacts on brain function using advanced neuroimaging methods such as functional magnetic resonance imaging (fMRI) studies. fMRI, measuring patterns in brain activity, has been used to examine the mechanisms underlying childhood-onset neuropsychiatric SLE as well as potential neurologically driven contributions to fibromyalgia and RA-associated fatigue (109-111). No studies have yet investigated fMRI data in individuals with myositis or looked at fMRI outcomes related to mental health burden among those with JDM. As depicted in Figure 1, there are a variety of relevant factors to consider when measuring baseline mental health and potential confounding factors. With strong associations between fatigue, sleep difficulties and mental health concerns in those with rheumatologic diseases, future studies should include fatigue and sleep as related to mental health in individuals with myositis (112). Psychological distress as related to appearance, body image and sexual health are additional avenues in need of further analysis, recognising prior studies that demonstrate strong relation between appearance concern and depression among those with SLE and RA (113). Other relevant measurable factors include disease severity, health-related trauma, loneliness and isolation, loss of control, pain, non-health related trauma exposure and health inequities. Clearly defined protocols are needed to identify distressed patients and guide follow-up planning and referral pathways for mental health care. Further research is needed to analyse outcomes of available interventions targeting disease-related anxiety, adjustment or coping and support for transition from paediatric to adult care (101). Interventions should also consider wrap-around services that support parents, caregivers, and other family members, recognising the broad impact of chronic illness on a family unit with higher-than-average levels of worry, worse physical functioning and affected family relationships when compared to normative populations (26, 114). Implementation of cognitive behavioural self-help interventions offer a cost-effective alternative to CBT for

individuals with myositis as well (115). Understanding resilience and its role in mental health for those with myositis is another important avenue for future research. Trials are needed to examine and implement a range of intervention types and add to the diversity of treatments and supports providers can confidently offer. Both psychological and rheumatology providers may benefit from training for myositis-specific psychological supports and therapies.

One phenomenological study of children with JDM demonstrated the importance of understanding the psychosocial effects of JDM on children. This study outlines the child's rollercoaster of emotions to help clinicians understand how to help patients at varying points in diagnosis (116). Future research should consider targeted interventions for those with myositis that account for the expected winding journey. One novel approach to offer connection among patients and insight for providers of the patient's mental health journey is the use of storytelling in group sessions with narrative-based techniques, as has been done with young adults with chronic rheumatologic illnesses (117). This pilot study demonstrated significant improvement in self-reported physical health following participation in the storytelling intervention, suggesting an important potential avenue to address the complex interplay of emotional and physical well-being. Poetry has also been used as an outlet for processing of disease diagnosis among individuals with myositis (118). Art, play, music, and dance therapy are other potential alternative therapeutic interventions that can be considered for those with myositis who experience significant mental health burden (119). Patient associations are also a critical point of contact for those who live with rare diseases like myositis that allows for connection to mitigate isolation and provides resources to understand underlying disease. Longitudinal studies are needed to understand long-term impact of these interventions and resources.

One study demonstrates the potential utility of animal-assisted intervention for individuals with rheumatologic conditions and psychiatric comorbidities,

offering another avenue for future investigation in those with myositis (120). Future studies should also consider the integration of spirituality as a pillar of support for individuals and families coping with mental health burden.

Intriguingly, a Norwegian study of 39 adults with JDM showed no difference in mental health functioning compared to 39 age-matched healthy controls (121). Though being a small sample size, with possibly insufficient power to detect a difference between the two groups, the results still provoke important questions as to whether mental health burden varies geographically, culturally or with resource-rich healthcare infrastructures. Future studies should investigate potential geographic disparities and potential local protective factors, with consideration of re-analysis of available data investigating baseline mental health burden among those with IIM (13).

Transition to adulthood is a vulnerable life stage for all individuals, but especially those with myositis, with risk of crisis as they cope with new providers and uncertainty (122). Future studies should investigate potential interventions and additional supportive mechanisms that target this transitional period to adult care. Furthermore, longitudinal studies understanding consequences of mental distress among youth with rheumatologic diseases are lacking. Studies of adults with JIA demonstrate worse mental health, lower QoL scores, and higher levels of unemployment compared to healthy counterparts (123, 124). Studies are needed that monitor the longitudinal mental health outcomes of young adults with juvenile myositis as they transition into adult care.

Further research is needed to establish effective educational programmes around mental health for paediatric and adult rheumatology providers. Funding is needed to support quality improvement initiatives and research seeking to improve mental health care for individuals with rheumatologic diseases. Understanding the mental health burden and potential avenues of intervention is critical to the biopsychosocial care model that addresses holistic subjective wellbeing of children and adults with myositis.

## Affiliations

<sup>1</sup>Seattle Children's Hospital and Research Center, University of Washington, Seattle, WA, USA;

<sup>2</sup>Women's Health and Health Professionals Theme, Medical Unit Occupational Therapy and Physical Therapy, Karolinska University Hospital, and Division of Rheumatology, Dept. of Medicine, Solna, Karolinska Institutet, Stockholm, Sweden;

<sup>3</sup>Dept. of Paediatrics, Division of Paediatric Rheumatology, Duke University School of Medicine, Durham, NC, USA;

<sup>4</sup>Cure JM Foundation, USA;

<sup>5</sup>School of Psychological Sciences and Health, University of Strathclyde, Glasgow, UK;

<sup>6</sup>Dutch Myositis Group at Spierziekten Nederland (Dutch patient association for NMD), Baarn, The Netherlands;

<sup>7</sup>Dept. of Rheumatology, Royal Wolverhampton Hospitals NHS Trust, Wolverhampton, UK;

<sup>8</sup>Division of Musculoskeletal and Dermatological Sciences, Centre for Musculoskeletal Research, School of Biological Sciences, The University of Manchester, UK;

<sup>9</sup>Dept. of Paediatrics, Division of Paediatric Rheumatology, Benioff Children's Hospital, University of California, San Francisco, CA, USA;

<sup>10</sup>Hospital for Sick Children, Division of Rheumatology, Toronto, Canada;

<sup>11</sup>SickKids Research Institute, Neurosciences and Mental Health Program; University of Toronto Temerty Faculty of Medicine, Toronto, Canada;

<sup>12</sup>The Myositis Association, USA;

<sup>13</sup>Great Ormond Street Children's Hospital, London, UK;

<sup>14</sup>Division of Rheumatology, University of Washington, Seattle, WA, USA;

<sup>15</sup>Women's Health and Allied Health Professionals Theme, Medical Unit Occupational Therapy and Physical, Karolinska University Hospital, Stockholm, Sweden;

<sup>16</sup>Dept. of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Stockholm, Sweden;

<sup>17</sup>Children's Hospital at Montefiore, Division of Paediatric Rheumatology, Bronx, NY, USA;

<sup>18</sup>Albert Einstein College of Medicine, Dept. of Paediatrics, Bronx, NY, USA;

<sup>19</sup>University of Michigan, Ann Arbor, MI, USA;

<sup>20</sup>Rehabilitation Center Klimmendaal Arnhem, The Netherlands;

<sup>21</sup>Radboud University Medical Center Nijmegen, The Netherlands;

<sup>22</sup>New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center, New Orleans, LA, USA;

<sup>23</sup>University Medical Center, Comprehensive Pulmonary Hypertension Center and Interstitial Lung Disease Clinic Programs, New Orleans, LA, USA;

<sup>24</sup>Louisiana State University School of Medicine, Section of Pulmonary Medicine, New Orleans, LA, USA;

<sup>25</sup>Tulane University School of Medicine, Undergraduate Honors Department, New Orleans, LA, USA.

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## References

- HOFFMANN JA, ATTRIDGE MM, CARROLL MS *et al.*: Association of youth suicides and county-level mental health professional shortage areas in the US. *JAMA Pediatr* 2023; 177: 71-80. <https://doi.org/10.1001/jamapediatrics.2022.4419>
- HUANG L, MACBETH G, DODGE J, JACOBSTEIN D: Transforming the workforce in children's mental health. *Admin Pol Ment Health* 2004; 32: 167-87. <https://doi.org/10.1023/b:apih.0000042745.64582.72>
- FINDLING RL, STEPANOVA E: The workforce shortage of child and adolescent psychiatrists: Is it time for a different approach? *J Am Acad Child Adolesc Psychiatry* 2018; 57: 300-1. <https://doi.org/10.1016/j.jaac.2018.02.008>
- WORLD HEALTH ORGANIZATION (2022): COVID-19 pandemic triggers 25% increase in prevalence of anxiety and depression worldwide. <https://www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-worldwide>. (Accessed September 19, 2023).
- FAIR DC, CUNNINGHAM NR, KNIGHT AM: The elephant in the room: Time to address mental health as a priority in pediatric rheumatology. *J Rheumatol* 2023; 50(6): 726-9. <https://doi.org/10.3899/jrheum.230057>
- RUBINSTEIN TB, OGBU EA, RODRIGUEZ M *et al.*: Prioritized agenda for mental health research in pediatric rheumatology from the Childhood Arthritis and Rheumatology Research Alliance Mental Health Workgroup. *J Rheumatol* 2020; 47: 1697-95. <https://doi.org/10.3899/jrheum.190361>
- ALEXANDERSON H, DEL GRANDE M, BINGHAM CO III *et al.*: Patient-reported outcomes and adult patients' disease experience in idiopathic inflammatory myopathies. Report from the OMERACT 11 Myositis Special Interest Group. *J Rheumatol* 2014; 41: 3. <https://doi.org/10.3899/jrheum.131247>
- O'MALLEY PG, JACKSON JL, KROENKE K, YOON K, HORNSTEIN E, DENNIS GJ: The value of screening for psychiatric disorders in rheumatology referrals. *Arch Intern Med* 1998; 158(21): 2357-62. <https://doi.org/10.1001/archinte.158.21.2357>
- GRAHAM CD, ROSE MR, GRUNFELD EA, KYLE SD, WEINMAN J: A systematic review of quality of life in adults with muscle disease. *J Neurol* 2011; 258: 1581-92. <https://doi.org/10.1007/s00415-011-6062-5>
- ACHTMAN J, KLING MA, FENG R, OKAWA J, WERTH VP: A cross-sectional study of untreated depression and anxiety in cutaneous lupus erythematosus and dermatomyositis. *J Am Acad Dermatol* 2016; 74: 377-9. <https://doi.org/10.1016/j.jaad.2015.09.016>
- SENN KC, THIELE S, KUMMER K, WALTER MC, NAGELS KH: Patient-reported health-related quality of life, anxiety and depression in patients with inclusion body myositis: A register-based cross-sectional study in Germany. *J Clin Med* 2023; 12: 5051. <https://doi.org/10.3390/jcm12155051>
- YOSHIDA A, LI Y, MAROUFY V *et al.*: Impaired health-related quality of life in patients with idiopathic inflammatory myopa-



- thies: A cross-sectional analysis from an international e-survey. *Ann Rheum Dis* 2023; 82 (Suppl. 1). <https://doi.org/10.1136/annrheumdis-2023-eular.1450>
13. MECOLI CA, PARK JK, ALEXANDERSON H *et al.*: Perceptions of patients, caregivers, and healthcare providers of idiopathic inflammatory myopathies: An international OMER-ACT study. *J Rheumatol* 2019; 46(1): 106-11. <https://doi.org/10.3899/jrheum/180353>
  14. TREEMARCKI EB, DANGUECAN A, CUNNINGHAM NR, KNIGHT AM: Mental health in pediatric rheumatology: An opportunity to improve outcomes. *Rheum Dis Clin North Am* 2022; 48(1): 67-90. <https://doi.org/10.1016/j.rdc.2021.09.012>
  15. RUBINSTEIN T, DAVIS A, RODRIGUEZ M, KNIGHT A: Addressing mental health in pediatric rheumatology. *Curr Treatm Opt Rheumatol* 2018; 4: 55-72.
  16. DAVIS AM, RUBINSTEIN TB, RODRIGUEZ M, KNIGHT AM: Mental health care for youth with rheumatologic diseases: Bridging the gap. *Ped Rheumatol* 2017; 15: 85. <https://doi.org/10.1186/s12969-017-0214-9>
  17. JONES JT, CUNNINGHAM N, KASHIKAR-ZUCK S, BRUNNER HI: Pain, fatigue and psychological impact on health-related quality of life in childhood-onset lupus. *Arthritis Care Res* 2016; 68: 73-80. <https://doi.org/10.1002/acr.22650>
  18. SHAW KL, SOUTHWOOD TR, DUFFY CM, MCDONAUGH JE: Health-related quality of life in adolescents with juvenile idiopathic arthritis. *Arthritis Rheum* 2006; 55: 199-207. <https://doi.org/10.1002/art.21852>
  19. DAVIS AM, GRAHAM TB, ZHU Y, MCPHEETERS MI: Depression and medication nonadherence in childhood-onset systemic lupus erythematosus. *Lupus* 2018; 27: 1532-41. <https://doi.org/10.1177/0961203318779710>
  20. TARAKCI E, YELDAN I, KAYA MUTLU E, BAYDOGAN SN, KASAPCOPIR O: The relationship between physical activity level, anxiety, depression and functional ability in children and adolescents with juvenile idiopathic arthritis. *Clin Rheumatol* 2011; 30: 1415-20. <https://doi.org/10.1007/s10067-011-1832-0>
  21. REID MR, FABRICIUS J, DANGUECAN A *et al.*: Anxiety and depression in childhood rheumatologic conditions: A topical review. *Ind J Rheumatol* 2021; 16(3): 304-10.
  22. LIM LS, EKUMA O, MARRIE RA *et al.*: Do patterns of early disease severity predict grade 12 academic achievement in youths with childhood-onset chronic rheumatic diseases? *J Rheumatol* 2023; 50(9): 1165-72. <https://doi.org/10.3899/jrheum.220656>
  23. LIVERMORE P, WEDDERBURN L: Assessing Psychosocial needs in Juvenile Dermatomyositis patients across the United Kingdom. *Arthritis Rheumatol* 2019; 71 (Suppl. 10).
  24. ARDALAN K, OLSON L, DVERGSTEN J *et al.*: Mental health screening in juvenile myositis: Preliminary analysis of a multicenter pilot study [Abstract]. *Arthritis Rheumatol* 2022; 74 (Suppl. 9).
  25. APAZ MT, SAAD-MAGALHAES C, PISTORIO A *et al.*: Health-related quality of life of patients with juvenile dermatomyositis: results from the paediatric rheumatology international trials organization multinational quality of life cohort study. *Arthritis Care Res* 2009; 61: 509-17. <https://doi.org/10.1002/art.24343>
  26. ARDALAN K, ADEYEMI O, WAHEZI DM *et al.*: Parent perspectives on addressing emotional health for children and young adults with juvenile myositis. *Arthritis Care Res* 2021; 73(1): 18-29. <https://doi.org/10.1002/acr.24466>
  27. SAUD A, NAVEEN R, AGGARWAL R, GUPTA L: COVID-19 and myositis: what we know so far. *Curr Rheumatol Report* 2021; 23(8): 63. <https://doi.org/10.1007/s11926-021-01023-9>
  28. PAKHCHANIAN H, HAN H, RAIKER R *et al.*: COVID-19 outcomes in patients with dermatomyositis: A registry-based cohort analysis. *Semin Arthritis Rheum* 2022; 56: 152034. <https://doi.org/10.1016/j.semarthrit.2022.152034>
  29. BELDI T, VINCEZ A, MILTENYI-SZABO Z *et al.*: The effect of COVID-19 pandemic on idiopathic inflammatory myositis patients: A single centre experience. *Clin Exp Rheumatol* 2023; 41: 254-60. <https://doi.org/10.55563/clinexp/rheumatol/eisexh>
  30. KHAROUF F, KENIG A, BOHBOT E *et al.*: Increased rates of idiopathic inflammatory myopathies during the COVID-19 pandemic: A single-centre experience. *Clin Exp Rheumatol* 2023; 41: 316-21. <https://doi.org/10.55563/clinexp/rheumatol/970881>
  31. CAVAGNA L, FERRO F, ZANFRAMUNDO G, LA ROCCA G, PUXEDDU I: Idiopathic inflammatory myopathies and COVID-19: An intriguing liaison? *Clin Exp Rheumatol* 2023; 41: 1-4. <https://doi.org/10.55563/clinexp/rheumatol/njaff0>
  32. NAVEEN R, SEN P, GRIGER Z *et al.*: Flares in IIMs and the timeline following CoVID-19 vaccination: A combined analysis of the COVAD-1 and -2 surveys. *Rheumatology* 2024; 63(1): 127-39. <https://doi.org/10.1093/rheumatology/kead180>
  33. GUPTA L, LILLEKER JB, AGARWAL V, CHINNOY H, AGGARWAL R: COVID-19 and myositis: Unique challenges for patients. *Rheumatology* 2021; 60: 907-10. <https://doi.org/10.1093/rheumatology/keaa610>
  34. ALI SS, NAVEEN R, SEN P *et al.*: Flares after COVID-19 infection in patients with idiopathic inflammatory myopathies: Results from the COVAD study. *Rheumatology* 2023; 62(9): e263-8. <https://doi.org/10.1093/rheumatology/kead149>
  35. REUTER K, DEODHAR A, MAKRI S, ZIMMER M, BERENBAUM F, NIKIPHOROU E: The impact of the COVID-19 pandemic on people with rheumatic and musculoskeletal diseases: Insights from patient-generated data on social media. *Rheumatology* 2021; 60: S177-84. <https://doi.org/10.1093/rheumatology/keab174>
  36. WAHEZI DW, JEROME D, ROTHSCHILD E *et al.*: The impact of the COVID-19 pandemic on patients with juvenile idiopathic inflammatory myopathies. *Ped Rheumatol Online J* 2023; 21(100): 1-8. <https://doi.org/10.1186/s12969-023-00873-0>
  37. AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY. Workforce Issues. [https://www.aacap.org/AACAP/Resources\\_for\\_Primary\\_Care/Workforce\\_Issues.aspx#:~:text=There%20are%20approxim](https://www.aacap.org/AACAP/Resources_for_Primary_Care/Workforce_Issues.aspx#:~:text=There%20are%20approxim)
  38. WHITNEY DG, PERERSON MD: US national and state level prevalence of mental health disorders and disparities of mental health care use in children. *JAMA Pediatr* 2019; 173(4): 389-391. <https://doi.org/10.1001/jamapediatrics.2018.5399>
  39. BRADDICK F, CARRAL V, JENKINS R, JANELLOPIS E: Child and adolescent mental health in Europe: Infrastructures, policy and programmes. [https://ec.europa.eu/health/ph\\_determinants/life\\_style/mental/docs/camhee\\_infrastructures.pdf](https://ec.europa.eu/health/ph_determinants/life_style/mental/docs/camhee_infrastructures.pdf). Accessed 19 Sept 2023.
  40. KNIGHT A, VICKERY M, FAUST L *et al.*: Gaps in mental health care for youth with rheumatologic conditions: A mixed methods study of perspectives from behavioral health providers. *Arthritis Care Res* 2018; 71(5). <https://doi.org/10.1002/acr.23683>
  41. LIVERMORE P, GIBSON P, MULLIGAN K *et al.*: Mapping the current psychology provision for children and young people with juvenile dermatomyositis. *Rheumatol Adv Pract* 2021; 5(3): rkab062. <https://doi.org/10.1093/rap/4kab062>
  42. ARDALAN K, FILLIPO R, ZIGLER C *et al.*: What happens after juvenile myositis patients screen positive for mental health comorbidities? Update from a multicenter juvenile myositis mental health screening pilot study. [Abstract] *Arthritis Rheumatol* 2023; 75(Suppl 4).
  43. ABAD VC, SARINAS SA, GUILLEMINAULT C: Sleep and rheumatologic disorders. *Sleep Med Rev* 2008; 12: 211-28. <https://doi.org/10.1016/j.smrv.2007.09.001>
  44. KOOL MB, GEENAN R: Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *J Psychol* 2012; 146: 229-41. <https://doi.org/10.1080/00223980.2011.606434>
  45. MEENAKSHI J: Body image issues in rheumatology. In CASH TF, SMOLAK L (Eds.): *Body image: A handbook of science, practice and prevention*. The Guilford Press 2011: 350-7.
  46. HALE ED, RADVANSKI DC, HASSETT AL: The man-in-the-moon face: A qualitative study of body image, self-image and medication use in systemic lupus erythematosus. *Rheumatology* 2015; 54(7): 1220-5. <https://doi.org/10.1093/rheumatology/keu448>
  47. KELLERMAN J, ZELTZER L, ELLENBERG L, DASH J, RIGLER D: Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. *J Pediatr* 1980; 97(1): 126-31. [https://doi.org/10.1016/s0022-3476\(80\)80152-1](https://doi.org/10.1016/s0022-3476(80)80152-1)
  48. ARESKOU-GIOSEFSSON K, OBERG U: A literature review of sexual health of women with rheumatoid arthritis. *Musculoskel Care* 2009; 7(4): 219-26. <https://doi.org/10.1002/msc.152>
  49. HEŘMÁNKOVÁ B, ŠPIRITOVÍČ M, ORESKÁ S *et al.*: Sexual function in patients with idiopathic inflammatory myopathies: a cross-sectional study. *Rheumatology* 2021; 60(11): 5060-72. <https://doi.org/10.1093/rheumatology/keab397>
  50. HEŘMÁNKOVÁ B, ŠPIRITOVÍČ M, ŠMUCROVÁ H *et al.*: Female sexual dysfunction and pelvic floor muscle function associated with systemic sclerosis: a cross-sectional study. *Int*

- J Environ Res Public Health* 2022; 19(1): 612. <https://doi.org/10.3390/ijerph19010612>
51. NEWMAN S, MULLIGAN K: The psychology of rheumatic diseases. *Baillieres Best Pract Res Clin Rheumatol* 2000; 14(4): 773-86. <https://doi.org/10.1053/berh.2000.0112>
  52. FALKENSTEIN DK, JARVIS JN: Health inequities in the rheumatic diseases of childhood. *Curr Opin in Rheumatol* 2022; 34(5): 262-6. <https://doi.org/10.1097/bor.0000000000000893>
  53. SALIHOGLU S, DOGAN SC, KAVAKCI O: Effects of childhood psychological trauma on rheumatic diseases. *Eur J Rheumatol* 2019; 6(3): 126-9. <https://doi.org/10.5152/eurjrheum.2019.18184>
  54. BEALE IL: Scholarly literature review: Efficacy of psychological interventions for pediatric chronic illness. *J Pediatr Psychol* 2006; 31: 437-51. <https://doi.org/10.1093/jpepsy/psj079>
  55. WESSELHOEFT R, SORENSEN MI, HELER-VANG ER, BILENBERG N: Subthreshold depression in children and adolescents: A systematic review. *J Affect Disord* 2013; 151: 7-22. <https://doi.org/10.1016/j.jad.2013.06.010>
  56. HALFIN A: Depression: The benefits of early and appropriate treatment. *Am J Manag Care* 2007; 13(Suppl. 4): S92-7.
  57. KUPFER DJ, FRANK E, PEREL JM: The advantage of early treatment intervention in recurrent depression. *Arch Gen Psychiatry* 1989; 46(9): 771-5. <https://doi.org/10.1001/archpsyc.1989.01810090013002>
  58. COULEHAN JL, SCHULBERG HC, BLOCK MR, MADONIA MJ, RODRIGUES E: Treating depressed primary care patients improves their physical, mental and social functioning. *Arch Intern Med* 1997; 157(10): 1113-20.
  59. NIXON J, GRAY L, TURNER J, BERNARD A, SCAIFE J, CARTMILL B: Communicating Actively Responding Empathically (CARE): comparison of communication training workshops for health professionals working in cancer care. *J Cancer Educ* 2020; 35: 54-60. <https://doi.org/10.1007/s13187-018-1439-0>
  60. FAUCHON C, FAILLENOT I, PERRIN AM *et al.*: Does an observer's empathy influence my pain? Effect of perceived empathetic or unempathetic support on a pain test. *Eur J Neurosci* 2017; 46: 2629-37. <https://doi.org/10.1111/ejn.13701>
  61. Caring for patients who have experienced trauma: ACOG Committee Opinion, number 825. *Obstet Gynecol* 2021; 137: e94-9. <https://doi.org/10.1097/aog.0000000000004326>
  62. Preventing Sexual Violence, Violence Prevention, Injury Center, CDC. Available online: <https://www.cdc.gov/violenceprevention/sexualviolence/fastfact.html> (accessed on 29 April 2021).
  63. BIRD CM, WEBB EK, SCHRAMM AT, TORRES L, LARSON C, DEROON-CASSINI TA: Racial discrimination is associated with acute posttraumatic stress symptoms and predicts future posttraumatic stress disorder symptom severity in trauma-exposed black adults in the United States. *J Trauma Stress* 2021; 34(5): 995-1004. <https://doi.org/10.1002/jts.22670>
  64. TEMKIN D, HARPER K, STRATFORD B, SACKS V, RODRIGUEZ Y, BARTLETT JD: Moving policy toward a whole school, whole community, whole child approach to support children who have experienced trauma. *J Sch Health* 2020; 90: 940-7. <https://doi.org/10.1111/josh.12957>
  65. HALL S, WHITE A, BALLAS J, SAXTON SN, DEMPSEY A, SAXER K: Education in trauma-informed care in maternity settings can promote mental health during the COVID-19 pandemic. *J Obstet Gynecol Neonatal Nurs* 2021; 50: 340-51. <https://doi.org/10.1016/j.jogn.2020.12.005>
  66. Infographic: 6 Guiding Principles to a Trauma-Informed Approach: CDC. Available online: [https://www.cdc.gov/cpr/informatics/6\\_principles\\_trauma\\_info.htm](https://www.cdc.gov/cpr/informatics/6_principles_trauma_info.htm) (accessed on 29 April 2021).
  67. ELWYN G, COCHRAN N, PIGNONE M: Shared decision making—the importance of diagnosing preferences. *JAMA Intern Med* 2017; 177: 1239-40. <https://doi.org/10.1001/jamainternmed.2017.1923>
  68. HUBER M, KNOTTNERUS JA, GREEN L *et al.*: How should we define health? *BMJ* 2011; 343: d4163. <https://doi.org/10.1136/bmj.d4163>
  69. CAREL H, KIDD IJ, PETTIGREW R: Illness as transformative experience. *Lancet* 2016; 388(10050): 1152-3. [https://doi.org/10.1016/s0140-6736\(16\)31606-3](https://doi.org/10.1016/s0140-6736(16)31606-3)
  70. DOLEZAL L, GIBSON M: Beyond a trauma-informed approach and towards shame-sensitive practice. *Humanit Soc Sci Commun* 2022; 9: 214. <https://doi.org/10.1057/s41599-022-01227-z>
  71. MCCracken LM, Vowles KE: Acceptance and commitment therapy and mindfulness for chronic pain: model, process, and progress. *Am Psychol* 2014; 69(2): 178-87. <https://doi.org/10.1037/a0035623>
  72. GRAHAM CD, GOUCK J, FERREIRA N, GILLANDERS D: The influence of psychological flexibility on life satisfaction and mood in muscle disorders. *Rehabil Psychol* 2016; 61(2): 210. <https://doi.org/10.1037/rep0000092>
  73. ROSE M, GRAHAM CD, O'CONNELL N *et al.*: A randomized controlled trial of acceptance and commitment therapy for improving quality of life in people with muscle diseases. *Psycholog Med* 2023; 53(8): 3511-24. <https://doi.org/10.1017/s0033291722000083>
  74. OKKERSEN K, JIMENEZ-MORENO C, WENNINGER S *et al.*: Cognitive behavioural therapy with optional graded exercise therapy in patients with severe fatigue with myotonic dystrophy type 1: A multicentre, single-blind, randomised trial. *Lancet Neurol* 2018; 17(8): 671-80. [https://doi.org/10.1016/s1474-4422\(18\)30203-5](https://doi.org/10.1016/s1474-4422(18)30203-5)
  75. CUNNINGHAM NR, MILLER A, ELY SL *et al.*: A multi-site pilot randomized clinical trial of the treatment and education approach for childhood-onset lupus (TEACH) program: Study design and CoVID-19 adaptations. *Pediatr Rheumatol Online J* 2023; 21: 61. <https://doi.org/10.1186/s12969-023-00835-6>
  76. ALEXANDERSON H: Exercise in myositis. *Curr Treatm Opt Rheumatol* 2018; 4(4): 289-98. <https://doi.org/10.1007/s40674-018-0113-3>
  77. ALEMO MUNTERS L, ALEXANDERSON H, CROFFORD LJ, LUNDBERG IE: New insights into the benefits of exercise for muscle health in patients with idiopathic inflammatory myositis. *Curr Rheumatol Rep* 2014; 16(7): 429. <https://doi.org/10.1007/s11926-014-0429-4>
  78. ALEXANDERSON H, DASTMALCHI M, ESBJÖRNSSON-LILJEDAHL M, OPAVA CH, LUNDBERG IE: Benefits of intensive resistance training in patients with chronic polymyositis or dermatomyositis. *Arthritis Rheum* 2007; 57(5): 768-77. <https://doi.org/10.1002/art.22780>
  79. ALEXANDERSON H: Physical exercise as treatment for adult and juvenile myositis. *J Intern Med* 2016; 280: 75-96. <https://doi.org/10.1111/joim.12481>
  80. SPIRITOVIC M, HERMANKOVA B, ORESKA S *et al.*: The effect of a 24-week training focused on activities of daily living, muscle strengthening, and stability in idiopathic inflammatory myopathies: A monocentric controlled study with follow-up. *Arthritis Res Ther* 2021; 23: 173. <https://doi.org/10.1186/s13075-021-02544-5>
  81. ALEMO MUNTERS L, DASTMALCHI M, ANDGREN V *et al.*: Improvement in health and possible reduction in disease activity using endurance exercise in patients with established polymyositis and dermatomyositis: A multicenter randomized controlled trial with a 1-year open extension followup. *Arthritis Care Res* 2013; 65(12): 1959-68. <https://doi.org/10.1002/acr.22068>
  82. BRADY SM, FENTON SAM, METSIOS GS *et al.*: Different types of physical activity are positively associated with indicators of mental health and psychological wellbeing in rheumatoid arthritis during COVID-19. *Rheumatol Int* 2021; 41: 335-44. <https://doi.org/10.1007/s00296-020-04751-w>
  83. SAUD A, ABBASI M, MERRIS H *et al.*: Harnessing the benefits of yoga for myositis, muscle dystrophies and other musculoskeletal disorders. *Clin Rheumatol* 2022; 41(11): 3285-97. <https://doi.org/10.1007/s10067-022-06280-2>
  84. TO-MILES F, HÅKANSSON C, WAGMAN P, BACKMAN CL: Exploring the associations among occupational balance and health of adults with and without inflammatory arthritis. *Arthritis Care Res* 2022; 74: 22-30. <https://doi.org/10.1002/acr.24732>
  85. ROY L, ROUSSEAU J, FORTIER P, MOTTARD JP: Patterns of daily time use of young adults with or without first-episode psychosis. *Occupat Ther Ment Health* 2013; 29(3): 232-45. <https://doi.org/10.1080/0164212X.2013.819549>
  86. PATER R, GARMENDIA J, GALLAIS B *et al.*: 267<sup>th</sup> ENMC International workshop: Psychological interventions for improving quality of life in slowly progressive neuromuscular disorders. *Neuromusc Disord* 2023; 33: 562-9. <https://doi.org/10.1016/j.nmd.2023.03.012>
  87. HUBER M, KNOTTNERUS JA, GREEN L *et al.*: How should we define health? *BMJ* 2011; 343: d4163. <https://doi.org/10.1136/bmj.d4163>
  88. SAKETKOO LA, RUSSELL AM, PATTERSON KC, OBI ON, DRENT M: Sarcoidosis and frailty: recognizing factors that foster holistic resilience. *Curr Opin Pulm Med* 2023; 29(5): 501-11. <https://doi.org/10.1007/s11926-014-0429-4>

- doi.org/10.1097/mcp.0000000000000990
89. LIVERMORE P, AINSWORTH S, BEESLEY R *et al.*: 'The current mental health status of children and young people with JIA, and their wider family': a charity partner collaboration survey. *Pediatr Rheumatol Online J* 2023; 21: 111. <https://doi.org/10.1186/s12969-023-00898-5>
  90. GEENEN R, NEWMAN S, BOSSEMA E, VRIEZKOLK J, BOELEN PA: Psychological interventions for patients with rheumatic diseases and anxiety or depression. *Best Pract Res Clin Rheumatol* 2012; 26: 305-19. <https://doi.org/10.1016/j.berh.2012.05.004>
  91. CORATHERS SD, KICHLER J, JONES NH *et al.*: Improving depression screening for adolescents with type 1 diabetes. *Pediatrics* 2013; 132: e1396-402. <https://doi.org/10.1542/peds.2013-0681>
  92. QUITTNER AL, ABBOTT J, GEORGIOPOULOS AM *et al.*: International committee on mental health in cystic fibrosis: Cystic fibrosis foundation and European cystic fibrosis society consensus statements for screening and treating depression and anxiety. *Thorax* 2016; 71: 26-34. <https://doi.org/10.1136/thoraxjnl-2015-207488>
  93. SHENOI S, EDISON SE, HAYNES S, PATTEN J: Implementation of an embedded behavioral health care model in a pediatric rheumatology subspecialty juvenile myositis clinic. *Front Psychiatr* 2023; 14. <https://doi.org/10.3389/fpsy.2023.1192711>
  94. GOLDSTEIN-LEEVEER A, BEARER C, SIVARAMAN V *et al.*: Increasing access to psychological services within pediatric rheumatology care. *Pediatr Rheumatol Online J* 2023; 21: 51. <https://doi.org/10.1186/s12969-023-00837-4>
  95. ARAFAT MY, ZAMAN S, HAWLADER MDH: Telemedicine improves mental health in COVID-19 pandemic. *J Glob Health* 2021; 11: 03004. <https://doi.org/10.7189/jogh.11.03004>
  96. FRYE WS, GARDNER L, MATEUS JS: Utilising telemental health in a paediatric outpatient psychology clinic: Therapeutic alliance and outcomes. *Couns Psychother Res* 2022; 22(2): 322-30. <https://doi.org/10.1002/capr.12450>
  97. MCMILLAN JA, LAND M JR, LESLIE LK: Pediatric residency education and the behavioral mental health crisis: a call to action. *Pediatrics* 2017; 139: e20162141. <https://doi.org/10.1542/peds.2016-2141>
  98. PINOTTI C, MANNING A, EDISON S, SADUN R: A mental health workshop for pediatric rheumatology fellows [abstract]. *Arthritis Rheumatol* 2023; 75 (Suppl. 9). <https://acrabstracts.org/abstract/a-mental-health-workshop-for-pediatric-rheumatology-fellows/>. Accessed September 25, 2023.
  99. EL TAL T, ARDALAN K, CUNNINGHAM N *et al.*: The mosaic of mental health: Perceived impact of a workshop empowering pediatric rheumatology clinicians in routine screening and effective management of mental health problems [abstract]. *Arthritis Rheumatol* 2023; 75 (Suppl 4).
  100. SCHNEIDER S, JUNGHAENEL DU, KEEFFE FJ *et al.*: Individual differences in the day-to-day variability of pain, fatigue, and well-being in patients with rheumatic disease: Associations with psychological variables. *Pain* 2012; 153(4): 813-22. <https://doi.org/10.1016/j.pain.2012.01.001>
  101. FAWOLE OA, REED MV, HARRIS JG *et al.*: Engaging patients and parents to improve mental health intervention for youth with rheumatological disease. *Pediatr Rheumatol Online J* 2021; 19: 19. <https://doi.org/10.1186/s12969-021-00503-7>
  102. KELLY KM, SMITH JA, MEZUK B: Depression and interleukin-6 signaling: A mendelian randomization study. *Brain Behav Immun* 2021; 95: 106-14. <https://doi.org/10.1016/j.bbi.2021.02.019>
  103. GRAHAM-ENGELAND J, DEMEO NN, JONES DR *et al.*: Individuals with both higher recent negative affect and physical pain have higher levels of C-reactive protein. *Brain Behav Immun Health* 2022; 21: 100431. <https://doi.org/10.1016/j.bbih.2022.100431>
  104. PRATT J, HALL J: Biomarkers in neuropsychiatry: A prospect for the twenty first century? *Curr Top Behav Neurosci* 2018; 40: 3-10. [https://doi.org/10.1007/7854\\_2018\\_58](https://doi.org/10.1007/7854_2018_58)
  105. DEL GRANDE DA SILVA G, WIENER CD, BARBOSA LP *et al.*: Pro-inflammatory cytokines and psychotherapy in depression: Results from a randomized clinical trial. *J Psychiatr Res* 2016; 75: 57-64. <https://doi.org/10.1016/j.jpsychires.2016.01.008>
  106. HIMMERICH H, PATSALOS O, LICHTBLAU N, IBRAHIM MAA, DALTON B: Cytokine research in depression: Principles, challenges and open questions. *Front Psychiatry* 2019; 10: 30. <https://doi.org/10.3389/fpsy.2019.00030>
  107. ARDALAN K, DAVALOS A, HONG H *et al.*: Cross-sectional associations of emotional distress and cardiovascular health in juvenile lupus and dermatomyositis. [Abstract] *Arthritis Rheumatol* 2023; 75(suppl 9).
  108. NORDGAARD J, SASS LA, PARNAS J: The psychiatric interview: validity, structure and subjectivity. *Eur Arch Psychiatry Clin Neurosci* 2013; 263(4): 353-64. <https://doi.org/10.1007/s00406-012-0366-z>
  109. DIFRANCESCO MW, HOLLAND SK, RIS D *et al.*: Functional magnetic resonance imaging assessment of cognitive function in childhood-onset systemic lupus erythematosus. *Arthritis Rheum* 2007; 56(12): 4151-63. <https://doi.org/10.1002/art.23132>
  110. BASU N, KAPLAN CM, ICHECO E *et al.*: Functional and structural magnetic resonance imaging correlates of fatigue in patients with rheumatoid arthritis. *Rheumatology* 2019; 58(10): 1822-30. <https://doi.org/10.1093/rheumatology/kez132>
  111. PAMFIL C, CHOY EHS: Functional MRI in rheumatic diseases with a focus on fibromyalgia. *Clin Exp Rheumatol* 2018; 36 (Suppl. 114): S82-5
  112. WOLFE F, HAWLEY DJ, WILSON K: The prevalence and meaning of fatigue in rheumatic disease. *J Rheumatol* 1996; 23(8): 1407-17.
  113. MONAGHAN SM, SHARPE L, DENTON F *et al.*: Relationship between appearance and psychological distress in rheumatic diseases. *Arthritis Rheum* 2007; 15(2): 303-9. <https://doi.org/10.1002/art.22533>
  114. KOUNTZ-EDWARDS S, AOKI C, GANNON C, GOMEZ R: The family impact of caring for a child with juvenile dermatomyositis. *Chronic Illn* 2017; 13(4): 262-74. <https://doi.org/10.1177/1742395317690034>
  115. GARNEFSKI N, KRAAIJ V, BENOIST M *et al.*: Effect of a cognitive behavioral self-help intervention on depression, anxiety, and coping self-efficacy in people with rheumatic disease. *Arthritis Care Res* 2012; 65(7): 1077-84. <https://doi.org/10.1002/acr.21936>
  116. LIVERMORE P, SUZANNE G, MULLIGAN K *et al.*: Being on the juvenile dermatomyositis rollercoaster: A qualitative study. *Pediatr Rheumatol Online J* 2019; 17(1): 30. <https://doi.org/10.1186/s12969-019-0332-7>
  117. LANIS A, TU E, PESKIN M, MELENDEZ M *et al.*: Storytelling of young adults with chronic rheumatologic illnesses: A pilot study. *Healthcare* 2022; 10(10): 1979. <https://doi.org/10.3390/healthcare10101979>
  118. LIVERMORE P, WEDDERBURN LR, GIBSON F: You give me a name that I can't say, but I have to explain what it is every day: the power of poetry to share stories from young people with a rare disease. *J Poetry Therapy* 2020; 33: 20-9. <https://doi.org/10.1080/08893675.2020.1694210>
  119. VIJAYAN S, BANSAL K, GOEL A, OUARDOUZ S, NUNE A, GUPTA L: The continuum of art and rheumatology: A discernment of mutual inclusivity. *Rheumatol Int* 2022; 42(4): 571-9. <https://doi.org/10.1007/s00296-022-05092-6>
  120. KIESEWETTER J, HERBACH N, LANDES I *et al.*: Dog assisted education in children with rheumatic diseases and adolescents with chronic pain in Germany. *GMS J Med Educ* 2023; 40(4): Doc44. <https://doi.org/10.3205/zma001626>
  121. TOLLISEN A, SANNER H, FLATO B, WAHL AK: Quality of life in adults and juvenile-onset dermatomyositis: A case-control study. *Arthritis Care Res* 2012; 64(7): 1020-7. <https://doi.org/10.1002/acr.21637>
  122. PALMAN J, MCDONAGH JE: Young minds: Mental health and transitional care in adolescent and young adult rheumatology. *Open Access Rheumatol* 2020; 12: 309-21. <https://doi.org/10.2147/OARRR.S228083>
  123. FOSTER HE, MARHSALL N, MYERS A, DUNKLEY P, GRIFFITHS ID: Outcomes in adults with juvenile idiopathic arthritis: a quality of life study. *Arthritis Rheum* 2003; 48: 767-75. <https://doi.org/10.1002/art.10863>
  124. BARTH S, HAAS JP, SCHLSCHTIGER J *et al.*: Long-term health-related quality of life in German patients with juvenile idiopathic arthritis in comparison to German general population. *PLoS One* 2016; 11: e0153267. <https://doi.org/10.1371/journal.pone.0153267>
  125. JULIAN LJ: Measures of anxiety. *Arthritis Care Res* 2011; 63(11). <https://doi.org/10.1002/acr.20561>
  126. ARNOLD LM, CLAUW D, WANG F, AHL J, GAYNOR PJ, WOHLREICH MM: Flexible dosed duloxetine in the treatment of fibromyalgia: a randomized, double-blind, placebo-controlled trial. *J Rheumatol* 2010; 37: 2578-86. <https://doi.org/10.3899/jrheum.100365>
  127. KYVSGAARD N, THASTUM M, MIKKELSEN TS, CHRISTENSEN AE, HERLIN T: Coping strategies and anxiety in association with methotrexate-induced nausea in juvenile idiopathic arthritis. *Rheumatol Int* 2020; 40: 591-8. <https://doi.org/10.1007/s00296-020-04520-9>

128. SCOPAZ KA, PIVA SR, WISNIEWSKI S, FITZGERALD GK: Relationships of fear, anxiety, and depression with physical function in patients with knee osteoarthritis. *Arch Phys Med Rehabil* 2009; 90: 1866-73. <https://doi.org/10.1016/j.apmr.2009.06.012>
129. PETRI M, KALITERNA DA, PERKOVI D, NUIC M, BOZIC I: Anxiety and depression in inflammatory rheumatic diseases. *Rheumatol (Sunnyvale)* 2015; 5: 3.
130. LEE SJ, KANG EH, CHUNG SW *et al.*: Cancer risks in Korean patients with myositis: Comparison between cancers related and unrelated to myositis activity. [Poster presentation] *Ann Rheum Dis* 2015; 74: 832. <https://doi.org/10.1136/annrheumdis-2015-eular.3401>
131. BARTH S, HAAS JP, SCHLSCHTIGER J *et al.*: Long-term health-related quality of life in German patients with juvenile idiopathic arthritis in comparison to German general population. *PLoS One* 2016; 11: 30153267. <https://doi.org/10.1371/journal.pone.0153267>
132. DIRENZO D, BINGHAM CO, MECOLI CA: Patient-reported outcomes in adult idiopathic inflammatory myopathies. *Curr Rheumatol Rep* 2019; 21(11): 62. <https://doi.org/10.1007/s11926-019-0862-5>
133. TOUSSAINT A, HUSING P, GUMZ A *et al.*: Sensitivity to change and minimal clinically important difference of the 7-item Generalized Anxiety Disorder Questionnaire (GAD-7). *J Affect Disord* 2020; 265: 395-401. <https://doi.org/10.1016/j.jad.2020.01.032>
134. HAMILTON M: The assessment of anxiety states by rating. *Br J Med Psychol* 1959; 32: 50-5. <https://doi.org/10.1111/j.2044-8341.1959.tb00467.x>
135. AL-FADL EMA, ISMAIL MA, THABIT M, EL-SEROGY Y: Assessment of health-related quality of life, anxiety and depression in patients with early rheumatoid arthritis. *Egypt Rheumatol* 2014; 36(2): 51-6. <https://doi.org/10.1016/j.ejr.2013.12.004>
136. LIAO JZ, QI M, ZHU M, LUO FM: The prevalence and risk factors for anxiety/depression in patients with connective tissue disease (CTD) associated interstitial lung diseases (ILDs). *Research Square* 2022 March 31. <https://doi.org/10.21203/rs.3.rs-1477946/v1>
137. VALTYSDOTTIR ST, GUDBJORNSSON B, LINDQVIST U, HALLGREN R, HETTA J: Anxiety and depression in patients with primary Sjögren's syndrome. *J Rheumatol* 2000; 27: 165-9.
138. ERTENLI I, OZER S, KIRAZ S *et al.*: Infliximab, a TNF-alpha antagonist treatment in patients with ankylosing spondylitis: the impact on depression, anxiety and quality of life level. *Rheumatol Int* 2012; 32(2): 323-30. <https://doi.org/10.1007/s00296-010-1616-x>
139. BUSZEWICZ M, RAIT G, GRIFFIN M *et al.*: Self-management of arthritis in primary care: randomised controlled trial. *BMJ* 2006; 333: 879. <https://doi.org/10.1136/bmj.38965.375718.80>
140. MURPHY H, DICKENS C, CREED F, BERNSTEIN R: Depression, illness perception and coping in rheumatoid arthritis. *J Psychosom Res* 1999; 46: 155-64. [https://doi.org/10.1016/s0022-3999\(98\)00073-7](https://doi.org/10.1016/s0022-3999(98)00073-7)
141. CAULI A, GLADMAN DD, MATHIEU A *et al.*: Patient global assessment in psoriatic arthritis: a multicenter GRAPPA and OMERACT study. *J Rheumatol* 2011; 38: 898-903. <https://doi.org/10.3899/jrheum.100857>
142. MAK A, TANG C, CHAN M-F, CHEAK A, HO R: Damage accrual, cumulative glucocorticoid dose and depression predict anxiety in patients with systemic lupus erythematosus. *Clin Rheumatol* 2011; 30: 795-803. <https://doi.org/10.1007/s10067-010-1651-8>
143. ANDREASSON K, SANDLUNG H, ALEXANDERSON H: Patients with inflammatory myopathies who do not reach health enhancing levels of physical activity report higher levels of anxiety and depression: A cross sectional study of self-reported data. *Health Professionals in Rheum Abstracts* 2020.
144. EVERS AWM, KRAAIMAAT FW, GEENEN R, JACOBS JWJ, BIJLSMA JWJ: Longterm predictors of anxiety and depressed mood in early rheumatoid arthritis: A 3 and 5 year followup. *J Rheumatol* 2002; 29(11): 2327-36.
145. VRIEZKOLK J, EIJSBOUTS A, EVERS A, STENGER A, VAN DEN HOOGEN F, VAN LANKVELD W: Poor psychological health status among patients with inflammatory rheumatic diseases and osteoarthritis in multidisciplinary rehabilitation: Need for a routine psychological assessment. *Disabil Rehabil* 2010; 32(10): 836-44. <https://doi.org/10.3109/09638280903323250>
146. LIU W, DINDO L, HADLANDSMYTH K *et al.*: Item response theory analysis: PROMIS anxiety form & generalized anxiety disorder scale. *West J Nurs Res* 2022; 44(8): 765-72. <https://doi.org/10.1177/01939459211015985>
147. DAFFIN M, GIBLER RC, KASHIKAR-ZUCK S: Measures of juvenile fibromyalgia: Pain and symptom assessment tool (PSAT), PROMIS Pain Interference Anxiety and Depression scales, Functional Disability Inventory (FDI) and Pediatric Quality of Life (PedSQL) 3.0 Rheumatology Module. *Arthritis Care Res* 2020; 72 (Suppl 10): 171-82. <https://doi.org/10.1002/acr.24197>
148. PATEL RN, ESPARZA VG, LAI JS *et al.*: Comparison of patient-reported outcomes measurement information system computerized adaptive testing versus fixed short forms in juvenile myositis. *Arthritis Care Res* 2023; 75(2): 381-90. <https://doi.org/10.1002/acr.24760>
149. FIAR D, RODRIGUEZ M, KNIGHT AM, RUBINSTEIN TB: Depression and anxiety in patients with juvenile idiopathic arthritis: Current insights and impact on quality of life, a systematic review. *Open Access Rheumatol* 2019; 11: 237-52. <https://doi.org/10.2147/oarr.s174408>
150. KNIGHT A, WEISS P, MORALES K *et al.*: Depression and anxiety and their association with healthcare utilization in pediatric lupus and mixed connective tissue disease in patients: A cross-sectional study. *Ped Rheumatol Online J* 2014; 12: 42. <https://doi.org/10.1186/1546-0096-12-42>
151. SHAIN LM, PAO M, TIPTON MV *et al.*: Comparing parent and child self-report measures of the State-Trait Anxiety Inventory in children and adolescents with a chronic health condition. *J Clin Psychol Med Settings* 2020; 27(1): 173-81. <https://doi.org/10.1007/s10880-019-09631-5>
152. VANDYKE MM, PARKER JC, SMARR KL *et al.*: Anxiety in rheumatoid arthritis. *Arthritis Rheum* 2004; 51: 408-12. <https://doi.org/10.1002/art.20474>
153. WARD MM, MARX AS, BARRY NN: Psychological distress and changes in the activity of systemic lupus erythematosus. *Rheumatology (Oxford)* 2002; 41: 184-8. <https://doi.org/10.1093/rheumatology/41.2.184>
154. WHITE KP, NIELSON WR, HARTH M, OSTBYE T, SPEECHLEY M: Chronic widespread musculoskeletal pain with or without fibromyalgia: psychological distress in a representative community adult sample. *J Rheumatol* 2002; 29(3): 588-94.
155. BAGNATO G, VISALLI E, FIORENZA A *et al.*: Clinical, autoimmune and psychiatric parameters in systemic sclerosis and rheumatoid arthritis patients: Correlations with sleep disturbances. *Ann Rheum Dis* 2015; 74 (Suppl. 2): 824. <https://doi.org/10.1136/annrheumdis-2015-eular.2708>
156. SADJADI R, ROSE MR, MUSCLE STUDY GROUP: What determines quality of life in inclusion body myositis? *J Neurol Neurosurg Psychiatry* 2010; 81: 1164-6. <https://doi.org/10.1136/jnnp.2009.183863>
157. PISKIN D, ARICI ZS, KONUKBAY D *et al.*: Number of episodes can be used as a disease activity measure in familial Mediterranean fever. *Front Pediatr* 2022; 10: 822473. <https://doi.org/10.3389/fped.2022.822473>
158. LISITSYNA TA, VELTISHCHEV DY, SERAVINA OF *et al.*: Comparative analysis of anxiety-depressive spectrum disorders in patients with rheumatic diseases. *Ter Arkh* 2018; 90(5): 30-7. <https://doi.org/10.26442/terarkh201890530-37>
159. DORIA A, RINALDI S, ERMANI M *et al.*: Health-related quality of life in Italian patients with systemic lupus erythematosus. II. Role of clinical, immunological and psychological determinants. *Rheumatology* 2004; 43(12): 1580-6. <https://doi.org/10.1093/rheumatology/keh392>
160. ISCHENKO D, ALEKBEROVA Z, VELTISHCHEV D *et al.*: Anxiety-depressive spectrum and cognitive disorders in Behcet's disease patients. *Ann Rheum Dis* 2015; 74 (Suppl. 2): 1121-2. <https://doi.org/10.1136/annrheumdis-2015-eular.2495>
161. PAMUKCU M, DURAN TI, ULUSOY H, ALTINBAS K: Investigation of the correlation between mood disorder symptoms and disease activity and functional status in rheumatoid arthritis patients. *Turk J Med Sci* 2021; 51(6): 3008-16. <https://doi.org/10.3906/sag-2107-283>
162. INGEGNOLI F, SCHIOPPO T, UBIALI T *et al.*: Patient perceptions of depressive symptoms in rheumatic diseases: A cross-sectional survey. *J Clin Rheumatol* 2022; 28(1): e18-e22. <https://doi.org/10.1097/rhu.0000000000001564>
163. KHOULY RME, ELSABAGH HM, MOAWAD AAR, AFIFI S, HAWA MAAE: Functional and mental health affection (depression, anxiety, stress) among Egyptian rheumatic diseases patients during COVID-19 Pandemic. *Eur Rev Med Pharmacol Sci* 2022; 26: 4477-85. [https://doi.org/10.26355/eurrev\\_202206\\_29087](https://doi.org/10.26355/eurrev_202206_29087)
164. CORDEIRO RA, FISCHER FM, SHINJO SK: Work situation, work ability and expectation of returning to work in patients with systemic autoimmune myopathies. *Rheumatology* 2023; 62(2): 785-93. <https://doi.org/10.1093/rheumatology/keac389>