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Title: Mental health in pediatric and adult myositis-related diseases: Current state of research, interventions, and future steps from the *MIHRA Psychological Impact Scientific Working Group* 

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## ABSTRACT

**Introduction:** 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.

**Discussion:** Data related to mental health burden is limited by small sample size, limited generalizability, 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.

**Conclusion:** 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 characterize and prioritize the work ahead to understand baseline mental health burden and compare avenues for intervention.

**KEYWORDS**: myositis, myopathy, dermatomyositis, health-related quality of life, psychological, depression, anxiety, juvenile myositis, mental health

## 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 behavioral health providers.<sup>1-4</sup> Mental health-related concerns have been shown to impact Health-Related Quality of Life (HRQoL), educational and occupational attainment, treatment adherence, healthcare utilization and transition among those with pediatric and adult rheumatologic conditions, although literature in myositis is still lacking.<sup>5</sup> In 2020, the *Childhood Arthritis and Rheumatology Research Alliance (CARRA)* established a prioritized research agenda to address gaps in knowledge related to the mental health of youth with rheumatologic disease.<sup>6</sup> 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.<sup>7</sup> *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 characterize and prioritize 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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> Another study observed that one-fifth of those with inclusion body myositis (IBM) presented with significant levels of anxiety or depression.<sup>11</sup> Adults with IIMs in 48 countries similarly conveyed high cognitive impact, difficulty sleeping, and emotional distress.<sup>12</sup> One study comparing individuals with IIM to those with non-IIM autoimmune inflammatory rheumatic diseases (AIRD), 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).<sup>13</sup>

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%.<sup>14-16</sup> Recent studies distinguish individuals with childhood-onset rheumatologic disease as being at higher risk for mental health disorders than those with adult-onset disease.<sup>16</sup> Mental health symptoms in these children are associated with worse HRQoL, poor medication adherence, and potentially worse disease outcomes.<sup>17-21</sup> Disease severity has also been associated with decreased academic achievement among children diagnosed with childhood onset chronic rheumatic diseases.<sup>22</sup> 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.<sup>6, 21</sup> 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.<sup>23</sup> A subsequent multicenter 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.<sup>24</sup> Further, even those with well-controlled juvenile dermatomyositis (JDM) had significantly worse psychosocial functioning scores compared to healthy counterparts.<sup>25</sup> 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.<sup>26</sup> This study highlighted the differences in age-based experience of distress, recognizing 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.<sup>27, 28</sup> One study in Hungary found that patients with myositis had an increased risk of COVID-19 infection compared to national infection rates.<sup>28</sup> 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.<sup>29</sup> Several studies suggested a potential correlation between onset or flares of IIM with COVID-19 infection and/or vaccination.<sup>30-32</sup> 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.<sup>33, 34</sup> 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 recognizing 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 pediatric patients with IIM, raising concern around potential long-term effects of isolation and psychosocial stressors.<sup>35, 36</sup>

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.<sup>37</sup> Increasing workforce shortages and barriers to accessible quality mental healthcare are escalating this burden.<sup>38</sup> 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.<sup>39</sup> Echoing this, one-third of 100 CARRA centers, and nearly half of 15 United Kingdom (UK) centers, 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-born cost and time burden.<sup>40, 41</sup> A North American multicenter 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.<sup>42</sup> 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 pediatric 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 generalizability as well as varied methods for measurement including symptom screeners, and diagnosis codes to define mental health conditions.<sup>16</sup> Though under-utilized and some under-validated, more commonly used screening tools and symptom measures for anxiety and depression in adult and pediatric rheumatologic population are characterized in Table 1. This summary table excludes measures typically used to evaluate features specific to panic disorder, obsessive-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.<sup>43</sup> Loneliness has clear associations with biophysical-based survival outcomes comparable to cigarette smoking across the general population.<sup>44</sup> Loneliness and isolation are prevalent among individuals with rheumatic disease and are related to lack of social support, stigmatization and invalidation. Self-esteem and body image, challenged by diseaserelated body changes may also drive mental health burden among those with rheumatologic diseases.<sup>45-</sup> <sup>47</sup> 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.<sup>48-50</sup> Recognizing the impact of loss of control and potential healthrelated trauma, future studies are needed to investigate the role of these factors.<sup>51</sup> 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.<sup>52, 53</sup> 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 recognized and managed early.<sup>54, 55</sup> Early identification of depression in adults decreases the risk for major depression and suicide and improves social function and productivity.<sup>56-58</sup>

Beyond the early identification of mental health, person-centered 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.<sup>59-67</sup> These are non-threatening and power-equalizing 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.<sup>68-70</sup> Person-positive philosophies safeguard inter-communication fluency, personalization and

sustainability of holistic health strategies, and recognizes traditional medical tendencies of '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".<sup>71</sup> On the basis of an observational study that showed significant correlations between psychological flexibility and wellbeing and mood in muscle disorders, including myositis, a randomized controlled trial of ACT in adults with myopathies including IBM, was completed.<sup>72</sup> 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.<sup>73</sup> 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.<sup>74</sup> 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.<sup>75</sup>

Physical activity and exercise interventions in IIMs are associated with reduced muscle inflammation and increased repair.<sup>76-80</sup> The Mental health domain was significantly improved after 12 weeks of intensive aerobic and muscle endurance exercise in a group of patients with myositis.<sup>81</sup> 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.<sup>80</sup> However, positive studies in RA prompt considerations to more deeply investigate physical activity effects on mental health and psychological well-being in IIMs.<sup>82</sup> A systematic data review of venerable yogic practices in neuromuscular and other diseases extrapolated that vogic interventions appear to be safe and probably beneficial for chronic pain and mental health burden in those with myositis.<sup>83</sup> 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.<sup>84</sup> The importance of occupational balance is also described in young adults with mental illness who experienced being under-occupied with too little to do.<sup>85</sup> 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 foremost 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.<sup>86-90</sup>

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, recognizing 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.<sup>90</sup>

## 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.<sup>91, 92</sup> Roadmaps for integrating behavioral health care within pediatric rheumatology and juvenile myositis clinics demonstrate feasibility and provide guidance for replication.<sup>93, 94</sup> Integrated behavioral 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 behavioral health spending by 19% and offset medical costs by 20%.<sup>86</sup>

While integration of mental health services within pediatric 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.<sup>95</sup> 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 utilized telehealth.<sup>96</sup> This growing field deserves further understanding of potential utility, efficacy and barriers for implementation.

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

## 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 characterize and prioritize the work ahead (Table 3).

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. Recognizing potential for day-to-day variability in self-reported screening outcomes, future studies should strive to outline preferred screening administration intervals.<sup>100</sup> 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.<sup>24, 101</sup> 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.<sup>6</sup> Recent studies have shown a causal association between interleukin (IL) 6 signaling and depression, with other studies suggesting CRP concentration to be associated with negative affect, pain and inflammation.<sup>102, 103</sup> Burgeoning literature demonstrates utility of biomarkers for psychiatric diagnosis, prognosis and treatment, with additional literature investigating the role of proinflammatory cytokines on psychotherapy for depression.<sup>104-106</sup> 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.<sup>105,</sup> <sup>106</sup> 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.<sup>107</sup> 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.<sup>108</sup>

Another crucial piece in understanding the neuro-inflammatory role in mental health burden among those with myositis may be the characterization 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 RAassociated fatigue.<sup>109-111</sup> 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.<sup>112</sup> Psychological distress as related to appearance, body image and sexual health are additional avenues in need of further analysis, recognizing prior studies that demonstrate strong relation between appearance concern and depression among those with SLE and RA.<sup>113</sup> 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 analyze outcomes of available interventions targeting disease-related anxiety, adjustment or coping and support for transition from pediatric to adult care.<sup>101</sup> Interventions should also consider wrap-around services that support parents, caregivers, and other family members, recognizing 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.<sup>26, 114</sup> Implementation of cognitive behavioral self-help

interventions offer a cost-effective alternative to CBT for individuals with myositis as well.<sup>115</sup> 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.<sup>116</sup> 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.<sup>117</sup> 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.<sup>118</sup> 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.<sup>119</sup> 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.<sup>120</sup> 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.<sup>121</sup> 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 or not 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.<sup>13</sup>

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.<sup>122</sup> 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.<sup>123, 124</sup> 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 programs around mental health for pediatric 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.

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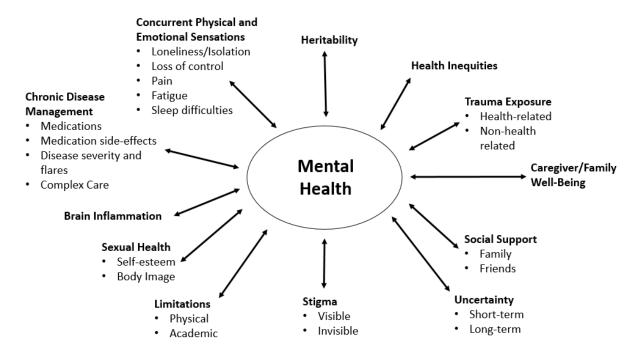


Figure 1. Conceptual model of measurable and relevant psychological factors.

**Table 1**. Instruments measuring anxiety and depression among children and adults with rheumatologic conditions.

See attached.

Table 2: Potential methods to address mental health burden among those living with myositis

\* = 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 Behavioral Therapy; SSRI: Selective serotonin reuptake inhibitors; SNRI: Serotonin and noradrenaline reuptake inhibitors.

Potential Resources
Psychological Interventions
ACT <sup>*</sup>
CBT <sup>*</sup> and Cognitive Behavioral Self-Help <sup>+</sup>
Disease education and psychoeducation
Talk and family therapy⁺
Pharmacologic Interventions
Biologics
SNRIs <sup>+</sup>
SSRIs⁺
Additional Therapeutic Interventions
Animal-assisted intervention <sup>+</sup>
Art, play, music and dance therapy $^{\scriptscriptstyle +}$
Embodiment Practices
Mindfulness⁺
Narrative Medicine and Poetry
Occupational balance <sup>*</sup>
Patient associations
Physical activity and exercise <sup>*</sup>
Resistance Strength Building <sup>*</sup>
Singing, humming, chanting
Spirituality
Yoga <sup>+</sup>

**Table 3:** Roadmap of future work in understanding and addressing mental health for individuals with myositis

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Future Avenues to Understand Mental Health in Myositis-Related Disorders
Understanding the Problem

- Characterize relevant baseline psychosocial factors (See figure 1)
- Validate mental health measures in myositis populations (See Table 1)
- Investigate biophysical measures in mental health including biomarkers and functional magnetic resonance imaging
- Investigate systemic, iatrogenic environmental and personal factors contributing toward resilience and holistic well-being
- Understand geographic disparities in mental health burden among individuals with myositis
- Characterize the impact of living with IIMs in early life with satisfaction of foundational education
- Characterize the impact of IIMs on occupational balance

Investigating Solutions and Establishing Next Steps

- Investigate and develop feasible interventions and models to maximize access to mental health care including:
  - Integration of mental health support strategies within clinics
  - Telehealth mental health services implementation
  - Training myositis specialists around identifying mental health burden and activating psychosocial supports
- Randomized control trials investigating outcomes of nonpharmacological mental health interventions (See Table 2)
- Identify and assess resilience and holistic well-being fortification strategies
- Assess and improve resources available during transition from pediatric to adult care
- Establish models of wrap-around services for significant others, parents, teachers, family, and siblings of individuals with myositis

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