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REVIEW

Young Minds: Mental Health and Transitional Care in Adolescent and Young Adult Rheumatology

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Abstract: Consideration of the mental health and emotional wellbeing is an important component of health care for all young people, irrespective of setting. Mental health disorders are common during adolescence and young adulthood and young people with rheumatic musculoskeletal diseases (RMD) are not exempt. For such young people, risks of poor outcomes are related to both mental health as well as their RMD. Times of change during adolescence and young adulthood—transitions—are potentially vulnerable life stages for young people with RMD and warrant specific attention in health care provision. Such transitions include those occurring at puberty, during education, training, and employment, socially with moves away from the parental home, as well as from child to adult-centered health services. There is great potential for rheumatology professionals to support young people with RMD at these transitions in view of their frequent encounters and ongoing therapeutic relationships. In this review, we aim to assess the impact of mental health on RMD during adolescence and young adulthood with particular reference to transitional care provision and how rheumatology professionals can be involved in addressing mental health issues during this time of change.

Keywords: adolescent, young adult, developmentally appropriate health care, transitional care, rheumatology, rheumatic musculoskeletal disease, mental health

Introduction

Mental health disorders are common during adolescence and young adulthood. Fifty percent of all lifetime mental health disorders (classified by DSM-IV) have an onset by 14 years, and 75% by 24 years of age.[1]

In the UK, 14.4% of 11–16 year olds and 16.9% of 17–19 year olds met the criteria for having a mental health disorder[2] with a trend for these disorders to increase in the early teens for both genders, and then to continue increasing into the late teens for young women. There is increasing concern that rates of emotional disorder are rising across the developed world.[3,4] At the time of writing there is an additional concern of the impact of the COVID-19 pandemic on the emotional wellbeing of young people.[5]

Young people with chronic disease (including rheumatic musculoskeletal disease, RMD)[6,7] have been reported to be more likely to have mental health disorders than healthy individuals, with some authors reporting up to a fourfold risk.[8–12] In certain RMDs, such as systemic lupus erythematosus (SLE), there are direct effects on the brain and nervous system caused by the condition itself resulting in additional psychological morbidity.[13]

Risks for poor outcomes in RMD conditions are often found to be related to both mental health status as well as their RMD. For example, in juvenile idiopathic arthritis (JIA), young people who experience symptoms of depression and anxiety

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have worse quality of life and furthermore these symptoms may have a greater impact on quality of life than the actual disease activity itself.[14]

During adolescence and young adulthood there are many transitions taking place whether they be biological in terms of puberty, social (development of intimate relationships, leaving the parental home), educational and vocational (moving schools, moving to university, starting the first job) as well as health transitions when young people move from child-centered to adult centered health services. Transitional care in health addresses the medical as well as the psychological, social, and educational/vocational issues as the young person moves from pediatric to adult health care.[15] There are now international recommendations available for how such care should be provided[16] which state that it should be developmentally appropriate.[17]

Rheumatology professionals are well placed both to identify and address mental health issues during adolescence and young adulthood in view of the frequent encounters and ongoing therapeutic relationships. This is particularly pertinent at the aforementioned transitions when, if the young person is ill-prepared for the changes these life stages bring, they can also become times of crisis. In this review we aim to assess the impact of mental health on RMD during adolescence with particular reference to transitional care provision and how rheumatology professionals can be involved in addressing mental health issues during this time of change. We searched the PubMed database for all full English language publications from the last 15 years (until June 2020) using search terms related to juvenile RMDs, adolescents, transitional care and mental health (depression and anxiety). Although there is a breadth of literature on mental health in juvenile RMD, there is less literature focussed on mental health during the health transition process.

Mental Health and RMD

Current literature on the prevalence and incidence of psychological morbidity in young people with rheumatic diseases, is of variable quality and quantity and predominantly cross-sectional, rather than longitudinal and largely centered on JIA rather than the less common RMD. More research in this area has therefore been called for[18,19] but a brief summary of current evidence is presented below.

JIA

Evidence from qualitative literature involving children and young people (CYP), categorizes the impact of JIA into six themes, many of which could be described as psychological, ie aversion to being different, striving for normality, stigma and misunderstanding, suspicion in uncertainty, managing treatment, and desire for knowledge.[20] Living with the unpredictability of relapsing and remitting conditions such as JIA can be particularly challenging for young people during adolescence. A systematic review considering the construct of illness uncertainty in young people including those with rheumatic conditions reported that illness uncertainty was associated with illness distress and poorer psychological functioning.[21]

Anxiety and depression in JIA has been studied in a comprehensive systematic review of 60 articles (28 articles within last 10 years).[14] Studies using validated screens for depressive or anxiety symptoms reported prevalence of clinically significant symptoms in the range of 7–36% and 7–64%, respectively.[14] Most studies reported worse depressive and anxiety in young people with JIA than healthy controls although a recent study reported no difference.[22] When compared to primary immunodeficiencies, CYP with JIA had similar rates of mood disorders; however, CYP with inflammatory bowel disease and cancer reported higher rates of depressive symptoms.[23–25]

When considering the individual JIA subtypes, some studies have reported differences between subtypes, eg young people with polyarticular disease scored significantly higher than oligoarticular and enthesitis related subtypes on depressive symptoms[26] whereas in others no such differences were found.[27]

Many authors have reported a correlation between disease activity markers and depressive symptoms although not sustained over time[26–28] and some studies failed to show such relationships.[22,29]

Hanns et al reported that in adolescents with JIA, anxiety and depressive symptoms were associated with pain, disability, and physician global assessment VAS, but not with markers of inflammation.[22]

Similar variation has been reported with disease outcomes. Several authors have reported a significant relationship between functional disability (as measured by the Childhood Health Assessment Questionnaire) and depression scores.[26–29]

SLE and Vasculitides

As with JIA, SLE can be challenging during childhood and adolescence. In one study, young people with SLE (aged 11–22 years) reported the key aspects of living with SLE to include: stigma, Illness uncertainty, psychological coping as well as managing disease and limitations which result.[30] In another study involving young people with SLE, parents' illness uncertainty regarding their child's condition correlated to the child's illness uncertainty, which then was associated with the child's mental health and wellbeing.[31] It therefore is important for rheumatology professionals to proactively acknowledge and address this uncertainty with both young people and their parents in routine clinical practice.

Objective neuropsychiatric manifestations of SLE such as stroke, seizures, or transverse myelitis are relatively easy to recognize clinically unlike the more subjective presentations of headache, cognitive impairment and mood disorders particularly when depression in this age group is not rare, with a reported prevalence of approximately 5% in early adolescence and 20% by late adolescence.[32] Research is ongoing for reliable noninvasive biomarkers in this age group to determine whether anxiety and depression is specifically related to disease activity.[33]

A systematic review by Quilter et al reported the prevalence of depressive symptoms in childhood onset SLE to be 6.7–59% and anxiety 34–37%.[13] In conditions such as SLE or other systemic vasculitides, as well as potential direct effects on the brain and nervous system caused by the condition itself, the impact of receiving a diagnosis such as these conditions and coming to terms with it, the relative rarity of the conditions, their potential severity, uncertainty of outcome and significant side effects of necessary drug therapy may all contribute to mental health in such young people. Young people (mean age 16.1 years) with SLE were found to have lower health related quality of life, with fatigue, pain, low mood, and anxiety as contributors to this.[34]

Younger adults with SLE (18–45), particularly those with juvenile-onset disease, ie diagnosed under the age of 18 years, are at high risk for major depression, which is associated with increased disease activity, poorer physical functioning, and lower educational attainment.[35] Early depression intervention in young adults with SLE has the potential to improve both medical and psychosocial outcomes.

In a qualitative study exploring the illness experience of young people with SLE (n=16), four reported adapting less well to the condition. The latter young people were experiencing challenges in more than one area and had lower psychological function, were older, of lower socioeconomic status and had increased disease-related morbidity. They also reported suboptimal treatment adherence, health-care utilization and transition to adult care[30] all potentially modifiable factors and core to any transitional care program.

Chronic Musculoskeletal Pain Syndromes

A major component of pediatric and adolescent rheumatology practice are young people with chronic idiopathic musculoskeletal pain. AYA with chronic pain report that they are less socially developed on virtually every metric than their peers.[36] The absence of inflammation or structural abnormality as the cause of the pain is often perceived by the young person and/or the family as diagnostic uncertainty which, as mentioned, is challenging to learn to live with.[37,38]

There is a strong and reciprocating relationship between anxiety and pain with over 80% of CYP with chronic pain meeting the criteria for an anxiety disorder.[39] Jastrowski Mano et al have proposed a developmentally informed shared vulnerability model to inform future research. This model postulates that young people at increased risk for the development of chronic pain and/or anxiety share predisposing vulnerabilities. These shared vulnerabilities then give rise to negative emotional responses (both in child and parent) in the context of stressful events. Consequences of fear and anxiety, including avoidance behavior, further contribute to the development of chronic pain, anxiety, and their co-occurrence.[39]

Current evidence supports the mainstay of management for such young people with a young person centered rehabilitation and pain management program involving psychology (often devised around a cognitive behavioral therapeutic model) as well as physiotherapy and occupational therapy.[40] For further discussion of this area, see Soltani et al.[41]

Specific Anxiety Inducing Procedures

Many RMD carry with them a burden related to managing the disease in terms of medications and blood test monitoring. In an observational study of CYP with JIA, methotrexate-induced nausea was associated with anxiety and the use of coping strategies. The authors proposed that psychological factors may therefore be part of the mechanism behind the inter-individual variation in the level of nausea to methotrexate treatment.[42] In another study of parents of 230 CYP with JIA on methotrexate for at least six months, fear of injections and/or blood tests rated as often or almost always was reported in over a third of CYP with over half reported as experiencing them at least sometimes. Anxiety related to blood tests was an independent predictor for poorer scores in the psychosocial scales of quality of life.[43] Intra-articular joint injections are another source of procedural pain particularly when done without general anesthetic. This is a particular challenge for young people transferring to adult rheumatology care when all such injections will be done when awake with only topical anesthetic. A potential compromise to support this gradual transition is reported by Elitsur et al[44] who reported that their minimal sedation/anxiolysis protocol (including nitrous oxide, intranasal fentanyl, a topical numbing agent, acetaminophen, ibuprofen, ondansetron and play therapy), provided safe and effective analgesia for intra-articular corticosteroid injection in a subset of CYP with JIA and offered a lower cost alternative to general anesthesia. It is important to note that doctors and nurses often underestimate procedural pain.[45]

It is also important not to make assumptions that all would choose anesthesia if given the choice. In one Spanish study 15 of 45 young people preferred without and gave reasons including quickness, fear of sedation, pre-sedation dizziness. Four did not express a preference.[46] In another study addressing injection training for subcutaneous drug administration, Sorenson et al reported that it was important for professionals and parents to use acknowledging communication styles with CYP and to offer sufficient coping strategies. The initial training session may have a great impact on long-term repeated injections by providing CYP with confidence from the outset.[47] Finally, addressing both child and parental anxieties about painful procedures is just as important as adequate analgesia.

Mental Health Within the Family

Parenting a child with a long-term health condition like JIA or SLE is challenging.[48] In their systematic review, Fair et al reported that there were high rates of anxiety and depression symptoms within family members of young people with JIA, which in turn may impact upon the mental health of the young people themselves.[14] In an all-age study of people with SLE (age range 12–73), associations were found between their quality of life and psychological status and that of their relatives.[49] In another large study of CYP with a range of chronic conditions including JIA, parents, especially mothers, reported high levels of anxiety and depression.[50] It therefore is important that mental health of the family is routinely considered in the assessment and management of young people with RMD.

Mental Health Outcomes in Adulthood

Outcomes for childhood-onset RMD have improved significantly in recent years since the advent of biologics. However, although disease activity measures improved at 15–30 years of follow-up, patient-reported outcomes in JIA including global well-being, quality of life, and functional ability scores did not.[51] Greater understanding of this disconnect is needed. Research into psychological outcomes across both inflammatory and noninflammatory RMD will help to explore which mechanisms are specific to inflammatory processes as well as those associated with the symptoms common to all RMD, eg pain, fatigue.

In recent years, adults with childhood onset RMD have been increasingly recognized rather than becoming lost within the larger populations of adult onset RMD. Of three such studies,[28,52,53] two reported a high prevalence of either depression or anxiety symptoms in adults with JIA.[28,53] In contrast, Raab reported significantly fewer adults with JIA reporting depressive symptoms compared to the general population.[52]

In young adults with SLE the prevalence of depression has been estimated to be 47% and after adjusting for age of onset, young adults with juvenile-onset SLE had higher risk of a major and recurrent depressive episodes odds ratio 1.7 (95%CI: 1.0–2.7) and 2.2 (95%CI: 1.2–4.3) respectively compared to adult-onset SLE.[35] In multiple adult studies, patients with SLE had higher prevalence of major depression, severe anxiety and emotional distress.[54,55] Overall meta-analysis of depression and anxiety in SLE was reported at 24% and 37%, respectively.[56] These studies show the high prevalence and associated mental health in SLE-related to disease activity and burden, aesthetics associated with medication and the disease's stigma and highlights the need for early mental health intervention.[57]

Work remains to ensure that a life course to rheumatology research is advocated and prospective long-term research following young people with childhood and adolescent onset disease into adulthood is both prioritized and enabled including funding. This will require particular attention to the peritransfer period to ensure effective mechanisms to follow these often geographically mobile young people so that they are not lost to follow-up and that the information gained is disseminated to CYP and families still in pediatric care.

Mental Health and Transition

Transition from pediatric to adult-centered health care is a particularly vulnerable period for adolescents and young adults (AYA). A study investigating the effect of transition of 50 young people with SLE in the absence of a formal transition program found that SLEDAI scores remained moderate but stable, however depression and anxiety and SLICC scores increased post-transfer.[58] The EULAR/PReS standards for transitional care[16] highlights the importance addressing psychological wellbeing during this life-stage in addition to the promotion of individual skills in self-care, self-determination,and self-advocacy. The latter skills have been reported to be associated with better transition outcomes.[59] The EULAR standards[16] also advocate the routine use of psychosocial screening tools during this time such as HEEADSSS, Home, Education, Eating, Activities, Drugs, Sex, Suicide and affect, safety,[60] which explicitly includes trigger questions to assess mental health and emotional well-being.

The different personalities and backgrounds of young people will play an important role in the approach that they will take to the transition process. These have been reported to group into four categories, namely anxious, laid-back, autonomy-seeking, and socially orientated.[61] In order to meet individual needs the clinician needs to adapt their therapeutic approach to parallel the young person. However, it is not yet known whether these categories remain consistent throughout the transition process, or change as the young person matures.

Psychological outcomes are rarely reported as a transition outcome[14] and the measuring of psychological outcomes in transitional research is seldom reported. A range of outcomes measures have been developed which assess the mental health of AYA.[62] According to the authors the most common clinician-reported outcome in mental health is the Children's Global Assessment Scale.[63,64] However, more composite scoring systems have been developed that contain CYP and parental indices and family functioning, with some of these scores being used as a routine clinical outcome measurement. The Strengths and Difficulties Questionnaire (SDQ) has been widely used to evaluate parent, carer, teacher, and patient reported outcome measures (PROM).[64] This scoring system focusses on the 11–17-year age range. Using PROMs is more time effective for secondary care and gains an insight into broader domains of home, education and social life than clinician-reported outcome measures. Serial SDQ scores can be supplemented by the Health of the Nation Outcome Scales: Child and Adolescent Mental Health to combine the patient and clinician-reported outcome measures.[65]

There are a range of transition readiness tools available including both generic or disease specific measures.[66] A rheumatology specific one has been reported in the early stages of development but like the others, did not include any specific mental health domains.[67] Readiness tools were developed as part of a large multicenter transitional care program in rheumatology which did include psychological domains[68] and have since been both used by some[69] and adopted in a generic format by others,[70] but these have not been validated.

The most widely used validated scoring system is the Transition Readiness Assessment Questionnaire (TRAQ) designed as a generic tool to aid clinicians in assessing the transition readiness of older adolescents and young adults (16–26 years).[71] Unfortunately, the scoring system has not been validated in younger adolescents (12–16 years) which shows the importance of developmentally appropriate outcome measures, and different developmental challenges that are faced during transition.[72] One could argue that many of the measures available are transfer rather than transition readiness tools focussing on the older adolescent rather than the more dynamic lengthy process of transition which starts in early adolescence. A more detailed score that has content validity across a wider age range (12–22 years) is the UNC TRxANSITION score uses 10 domains and the ability to cross-reference with medical history.[73,74] However, the tool, like TRAQ, must be individually examined for external validity as the domain of health insurance will not be applicable to all health care systems.

It is surprising that in spite of the significant psychological issues reported in the qualitative literature which surrounds transition,[75] that transitional readiness tools do not contain domains relating to mental health. A systematic review of barriers to transition only eluded to anxiety at the time of transition with the only mental health issue being the thought of terminating the relationship.[76] Due to the paucity of research, the study could not evaluate transition for any mental health related conditions nor mental health factors that may obstruct transition. Emotional issues have been reported as a primary contributor to transition difficulties resulting in poor symptom control, ongoing and new organ involvement.[77] The emotional experience of young people transferring to adult mental health services was reported to be characterized by the loss of relationships with clinicians and fear of less support in adult mental health services service.[78] It is therefore important to acknowledge the potential psychological impacts of the transition process itself and proactively address it in transitional care programs.

The system for transition from child and adolescent mental health services to the adult mental health service has been reported to inadequate compared to other health services.[79–81] Research into transition tools for mental health is under way with the published protocol for the development and validation procedure of the "managing the link and strengthening transition from child to adult mental health care (MILESTONE)" suite of measures.[81] How such tools will work at the interface between rheumatology and mental health services for those young people with RMD and a mental health comorbidity remains to be seen. Such young people will need a coordination of transition and transfer in order to be least disruptive to the management and ongoing care. Transfer at the point of a flare/relapse in either condition will increase the risk of a negative transfer and utilization of adult rheumatology services.

The transition from pediatric to adult services represents a fragile gap in health care. In both rheumatology and mental health there is a paucity of tools to support transition and transfer at the correct time. Poor judgement and inadequacies of the process are detrimental both to the individual and society. System level issues such as ensuring continuity of funding for drug therapies, eg biologics is an additional concern[82] and specifically highlighted in the EULAR recommendations.[16] Having rheumatic and mental health diseases is common, and therefore, robust interdisciplinary coordination of transition must be paramount to ensure a smooth transfer of care.

Another transition is that of the gradual transfer of responsibility for the management of both health and the RMD from the parent to the young person[83] who becomes the manager of their own health and therapy. Suboptimal treatment adherence and health-care utilization has been reported by young people with SLE, which in turn was associated with reduced psychological functioning.[30] Mental health and adherence have been reported to be closely linked.[84] In a recent integrative review, Zheng et al highlighted that studies in JIA were limited but that depressive symptoms did affect hospitalization rates/costs. The evidence in the diabetes literature was stronger and increased depressive symptoms in adolescents with diabetes predicted decreased metabolic control and monitoring, medication adherence and increased hospitalizations as well as quality of life.[85] Such evidence further supports the need for routine mental health assessment in rheumatology practice including when assessing adherence to medication, therapy and attendance at appointments, etc.

Transitions from primary to secondary education as well as the transition from statutory schooling to college/training/university/employment is another vulnerable period for adolescents. There are distinct age-related changes in social development and risk-taking behaviors as the adolescent brain develops which have been mapped to anatomical and biomechanical adaptations of the adolescent brain,[86,87] and in turn make such transitions challenging for all AYA, particularly so for those with mental health comorbidities. College students in the USA attributed 64% of mental health difficulties to nonattendance or withdrawal from college. Half of these students did not disclose a mental health condition, and more concerning, 73% had a reported crisis on campus.[88] The increase in autonomy for attending clinic appointments, taking medication and use of other therapies during the school/college day adds further pressures to adaptation to educational settings. A systematic review of nonadherence of psychotropic medication in AYA found an overall median of 33% (range: 6– 62%) not adhering to medication.[89] Furthermore four studies found an association between nonadherence and an increase in substance misuse.[89] Regular discussion of these issues during the transition period, remaining nonjudgemental and supportive, and highlighting the importance of getting further support from supervisors in education are useful measures clinicians can employ to minimize these risks.

A fundamental aspect of JIA is the chronicity of pain that has a significant impact on education and vocational development. CYP with chronic pain have a higher rate of absenteeism than other chronic health conditions.[90] The most common clinical manifestations of anxiety among CYP with chronic pain include school phobia, separation anxiety and social anxiety.[91] Specific school-related anxieties include the fear of academic failure, experiencing physical symptoms at school and negative peer evaluation.[90] Unfortunately, comprehensively measuring the impact of the chronic pain and chronic disease on school anxiety has not been established. Understanding the duality of chronic pain and disease burden on school related anxiety is incredibly important in JIA as pain often persists after treatment of the inflammatory phase.[92] Table 1 provides examples of important considerations for developmentally appropriate transitional care provision with specific reference to mental health

Mental Health Strategies and Interventions in Rheumatology Settings

A simple management strategy for all rheumatology professionals to adopt is to routinely introduce the concept of the psychological impact of all RMD at the time of diagnosis, irrespective of condition, for all young people and their families. Furthermore, discussing the impact of the condition on adolescent and young adult development is also important, emphasizing that one of the goals of management is to ensure developmental milestones are met and achieved whether they be biological, psychological, social, and/or vocational milestones.

In one study, young people with SLE and mixed connective tissue disease and their parents reported that pediatric rheumatologists were their preferred source for mental health screening, guidance and referral.[93] In a CARRA survey exploring mental health in SLE, however, 52% professional respondents reported inadequate identification of depression/anxiety while 77% felt routine mental screening should be conducted.[94] Barriers and facilitators for such screening have been identified both from the patient and the professional perspective (Table 2).[93–96] Interventions in this area potentially should aim to lift and/or remove these barriers while enhancing the facilitators and in so doing will potentially improve mental health care for young people with RMD.

Routine psychosocial screening tools such as HEEADSSS[60] are useful in this regard not only to engage young people, but also to identify both risk and protective factors. An App is now available as a useful aide memoire for trainees.[97] The potential of tablet-based screening tools with young people with long-term physical conditions are awaited with interest as they can be used prior to the actual consultation and the information gained can then inform the consultation, eg YouthCHAT (Youth version, case-finding and help assessment tool) which is an electronic, psychosocial screener for young people, which has been shown to be acceptable and feasible to use with young people with long-term physical conditions.[98]

Involvement of the multidisciplinary team (MDT) is imperative for managing young people with overlapping medical and mental health conditions. However,

Table 1 Transitional Care and Mental Health of Young People

Area of Transitional Care	Examples of Important Considerations for Developmentally Appropriate Transitional Care Provision with Specific Reference to Mental Health
Organizational	Coordination of care in peritransfer period to include mental health-care provision Inclusion of mental health related knowledge and skills in transition readiness check lists to ensure regular assessment Mental health training of rheumatology health professionals Ideally, specific psychological expertise within the rheumatology team in both adolescent and adult services, eg psychologist
Specific clinical issues	Routine developmental assessment during adolescence to assess whether young people are predominantly concrete thinkers or have developed abstract thought Adherence to therapy—nonadherence may be associated with low mood, anxiety, etc so important to routinely address in a nonjudgemental manner, eg when did you last forget to take your meds? Consideration of impact of having serious medical illness, eg SLE, juvenile dermatomyositis, vasculitides—potentially life-threatening Consideration of biographical disruption and adjusting to life with a long-term health condition Drug toxicity, eg depressed mood on corticosteroids SLE—risk of neuropsychiatric disease which may present subtly as headache, cognitive impairment or mood disorder Knowledge and skills in disclosure of condition to others Body image—steroid-related side effects particularly during peripubertal stage; skin rashes; lipodystrophy and calcinosis in juvenile dermatomyositis; localized growth impairment, eg limb length discrepancy in inflammatory arthritis; nasal cartilage loss in granulomatosis with polyangiitis

Table 2 Barriers and Facilitators to Addressing Mental Health Care in Rheumatology Clinics

Facilitators	Barriers
Strong clinician relationships	Stigma
Clinician initiative	Fear
Sincerity and normalization in discussing mental health by clinicians	Uncertainty about getting help
Increased patient/family awareness of mental health issues in RMD	Parental emotional burden
Opportunity for young person to be seen independent of caregivers	Minimization by health professionals
Enough time	Limited time
Assurance of confidentiality and how and when it would have to be breached	Limited staff resources
Routine psychosocial screening (eg HEEADSSS)	Lack of training of team members
Routinely introducing the concept of psychological impact at time of diagnosis	Limited mental health care access including long waiting lists
Involvement of the multidisciplinary team	Limited knowledge of local resources which young people can be signposted to

Note: Data from references [61] and [94,95,96,97].

psychological support for CYP with RMD in the UK is inadequate.[99] This is not surprising with the huge variability of access to psychology and psychiatry within the National Health Service (NHS), long waiting lists and low doctor–patient ratios compared to other European countries.[100,101] Tackling this problem may come through two means, either increasing the Child and Adolescent Mental Health Services, or by training the paediatric rheumatology MDT teams in supporting CYP with mental health.[102] Davis et al outlines that CYP with chronic rheumatological diseases would feel comfortable speaking to their rheumatologist about mental health concerns, especially as most CYP view their rheumatologists as their primary doctor as opposed to their general practitioner.[102] Currently most pediatric rheumatology MDTs are insufficiently prepared to straddle this dual responsibility.[94] However, integrating mental health training, clinical guidelines and support from child and adolescent mental health services may be a favourable balance to the chronic shortage of mental health services for this age group.

The systematic review by Fair et al identified a paucity of longitudinal studies which considered the impact of therapeutic intervention on mental health in the context of a RMD[14] echoing similar results of systematic reviews which considered long-term physical conditions.[103,104] Thabrew et al concluded that according to current evidence, therapies specifically designed to treat health-related anxiety in this age group were limited and that therapies specifically designed to treat anxiety or depression, especially those based on principles of cognitive behavior therapy (CBT), may be more likely to work in young people with mild to moderate symptoms of these disorders, at least in the short-term.[104] Results from research such as is proposed with the tailored CBT protocol for young people with SLE to address fatigue and depressive symptoms by Cunningham et al are awaited with interest.[105]

Workforce Competency and Service Level Issues

Ensuring workforce competency to address mental health issues remains imperative for rheumatology services. Pediatricians have been reported to identify only 25% of CYP meeting criteria for emotional/behavioral disorders[106] and family practitioners have been reported to have difficulty identifying mental health needs in CYP.[107] In a recent survey of 166 health professionals (including rheumatology professionals) involved in the care of young people (11–24 year olds), only 37% reported adequate knowledge and 35% skills to address mental health issues in this age group.[96] The major barrier reported by trainees in adult medicine was training with respect to this age group and the second barrier was time[108] echoing other studies,[109,110] including two addressing care of young people with SLE.[94,95] Attention is, therefore, needed with respect both to workforce competency in addressing mental health of young people with RMD and also how supportive the health-care system is to enable this to happen—how developmentally appropriate[111] and youth-friendly[112] is it? Are young people offered the opportunity to be seen independent of the caregiver, are the consultation times allocated long enough to enable mental health issues to be addressed? There are

Box 1 Key Messages

Significant Impact of RMD on Mental Health and Emotional Well-being
Key aspect of developmentally appropriate transitional care
Need to lift the existing barriers in routinely addressing mental health in rheumatology care settings
Adolescence and young adulthood have multiple transitions, one of which is health but all are potentially vulnerable times for AYA mental health
Mental health is an important health outcome for RMD as well as for transitional care
Significant need for more research in this area in the 10–24 year old age group

now useful tools available to evaluate such services, eg a benchmarking toolkit for adolescent and young adult rheumatology services.[113]

Research Challenges and the Way Forward

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) Mental Health Workgroup proposed five broad priority domains of mental health research namely (i) mental health burden and relationship to pediatric RMD, (ii) impact of mental health disorders on outcomes, (iii) mental health awareness and education, (iv) mental health screening, and (v) mental health treatment.[19] Of these, (i) and (ii) were rated as the most important and (iv) as the most feasible and actionable.[19] Box 1 summarizes the key messages from this current review.

Understanding the connections between physical and mental health in CYP becomes increasingly complicated with a lack of high-powered studies, scoring systems using parent-proxy measures and little understanding about the mechanics of physical-mental comorbidity in young people.[12] Studies such as the prospective Canadian MYLIFE study will be particularly informative in this regard.[114]

The evidence continues to sadly suggest that there remains a gap which still needs to be bridged between mental and physical health, never mind between pediatric and adult rheumatology. In future national and international standards for care and training curricula, mental health needs of young people with RMD will require greater prominence in order to improve service provision and workforce competency in this area. Furthermore, adoption of a life course approach to health research will enable consideration of mental health at the potentially vulnerable times of transition during adolescence and young adulthood—pubertal, social, educational, vocational as well as health-related transitions—as all have significant implications to health.

Abbreviations

RMD, rheumatic musculoskeletal disease; JIA, juvenile idiopathic arthritis; SLE, systemic lupus erythematosus; CYP, children and young people; AYA, adolescents and young adults; SLEDAI, SLE disease activity index; SLICC, Systemic Lupus International Collaborating Clinics; EULAR, European League Against Rheumatism; PReS, Paediatric Rheumatology European Society; HEEADSSS, Home, Education/Employment, Eating, Activities, Drugs, Sexuality, Suicidal ideation and Safety; SDQ, The Strengths and Difficulties Questionnaire; PROM, patient-reported outcome; TRAQ, Transition Readiness Questionnaire; CARRA, Childhood Arthritis and Rheumatology Research Alliance; MDT, multidisciplinary team; CBT, cognitive behavioral therapy.

Ethics Approval and Informed Consent

Not applicable.

Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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