Chapter 2
Impact of Rheumatic Musculoskeletal Disease on Psychological Development in Adolescents and Young Adults

Ran Alice Cai and Hema Chaplin

AYA Psychological Development

Psychological development in AYAs encompasses cognitive (see Chap. 1), emotional, and behavioural maturation [1]. A key process initiated by these psychological changes is the need to acquire a self-concept, which is how an individual perceives and thinks about the "self." It involves exploring and committing to identity-defining roles and values in a variety of life domains. Physical and hormonal changes during

R. A. Cai (✉)
Arthritis Research UK Centre for Adolescent Rheumatology, University College London, London, UK
e-mail: a.cai@ucl.ac.uk

H. Chaplin
Health Psychology Section, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
e-mail: hema.chaplin@kcl.ac.uk

J. E. McDonagh, R. S. Tattersall (eds.), *Adolescent and Young Adult Rheumatology In Clinical Practice*, In Clinical Practice,
https://doi.org/10.1007/978-3-319-95519-3_2

puberty also promote the development of a body image and a sexual identity. As a result, social (see Chap. 3) and physical components of the self-concept are of utmost importance during adolescence and have profound impacts on AYA psychological functioning [2].

Body image is based on a combination of one's own evaluation and the perception of others' attitudes towards one's physical characteristics [3]. A healthy body image means that the AYA accepts and appreciates his/her body and is generally satisfied with his/her appearance. Conversely, a negative body image occurs when there is a discourse between how the body is currently perceived and what the individual's preferences are.

Adolescence is also a time for discovering one's own sexual identity and for developing an interest in seeking intimate relationships. A sexual identity comprises of cognitive and emotional understandings that individuals have about the meaning and significance of their sexual attractions, behaviours, and relationships, as well as how they value and adopt certain gender roles [4]. Social interaction with peers is essential for acquiring important milestones to developing a sexual identity and forming healthy romantic relationships in the future, such as increased dating competence, subjective awareness of sexual orientation, and exploratory sexual experiences.

AYA self-concepts are relatively fluid due to dramatic physical and psychosocial changes, and they may develop multiple, conflicting self-representations [2]. Not being able to integrate opposing identities into one consistent and resilient self-concept can decrease self-esteem, which is how we evaluate and value our self-worth. For example, body dissatisfaction can be high among adolescents as they are more influenced than adults by external feedback and tend to compare themselves to cultural and societal standards. This can contribute to feelings of inferiority and low self-esteem, which can render AYAs more vulnerable to psychological problems [5]. Indeed, mild psychological problems affect about 40% of AYAs worldwide at some point in their lives [6].

Factors Influencing Psychological Wellbeing in AYAs

Whether or not AYAs experience psychological issues depends on the balance of risk and protective factors [7, 8]. Negative life events that cause chronic, prolonged stress, such as the consequences of RMD, are significant risk factors for AYA wellbeing [9]. One major issue is that the condition and its treatments can cause skin problems, delayed puberty, weight gain or loss, and shorter stature than healthy peers [10, 11]. The pain, fatigue, and mobility restrictions associated with RMD may also cause perceived physical weakness and poor fitness [12]. As a result, AYAs with RMD might compare themselves negatively to their peers, feel ashamed for being "different", and may even be concerned about experiencing stigmatisation [13]. Since AYAs of both genders can be equally concerned and self-critical about appearance [14], a negative body image can lead to low self-esteem and social withdrawal in all adolescents and can be a precursor to developing anxiety and depression [15].

Managing RMD can also restrict educational, social, and leisure participation, which can limit opportunities for psychosexual development that is often attained through interactions with peers [16, 17]. Moreover, physical limitations of RMD can interfere with an individual's ability to meet gender role demands. This may be particularly detrimental for boys, as small stature and thinness may be a significant source of sexual and gender-role anxiety due to embarrassment and fear of humiliation [18, 19].

In addition, being uncertain about whether or not they can achieve their full potential in personal and vocational endeavours despite the RMD is another major source of stress for AYAs [17]. The unpredictable nature of physical symptoms means that they need to accept the possibility of future flares or illness deterioration, and to continue a complicated treatment regimen (see Chap. 19) [17]. This can lead to guilt about potential dependency on intimate partners, which complicates the development of intimate relationships [20]. Many

AYAs also worry that their illness will compromise employment opportunities, which exacerbates the primary source of stress among all adolescents [17].

In order to prevent the escalation of chronic stress to psychological problems, AYAs should be equipped with skills and resources to cope with these challenging situations [7, 8]. HCPs can play an important role in providing AYAs with important protective factors, such as identifying maladaptive thought processes, providing social support, and promoting self-efficacy and autonomy [21, 22].

Psychological Support in Routine Practice

Primary Prevention: Coping Strategies

One of the most important protective factors from experiencing mental health difficulties is developing resilience, which is the ability to employ adaptive coping strategies. Coping can be viewed as the effort to regulate psychological and physiological processes, such as emotions, behaviours, and cognition, in response to stressful situations [23]. In the realm of managing chronic illness in adolescence, three subtypes of coping have been identified (see Fig. 2.1) [24]:

- **Active:** efforts to directly influence the stressor
- **Accommodative:** efforts to adapt to the stressor
- **Disengagement:** efforts to deny the stressor

Active and accommodative coping were found to increase resilience to stress, resulting in positive emotional and behavioural outcomes, whereas disengagement coping was associated with negative psychological adjustments [25].

Cognitive Distortions

The underlying principles of leading psychological therapies for AYAs are identifying and modifying cognitive distortions

FIGURE 2.1 Proposed relationships between cognitive processes, basic psychological needs, coping strategies, and mental health

in order to promote adaptive coping strategies [26, 27]. Two common distortions among AYAs are:

- **Catastrophizing**: having an overly negative and pessimistic perception about how long symptoms will last and the consequences of illness.
- **Mental filters:** paying attention to and drawing conclusions from only one type of evidence, such as comparing oneself negatively to others by only focusing on personal failures and other people's successes.

HCPs can help AYAs recognise and challenge these irrational thinking styles by encouraging alternative ways of thinking or reassessing the situation in a more positive and realistic way (see Chap. 4) [26, 27]. For example, AYA can be asked to consider all the evidence for and against their beliefs and assumptions, and to identify potential benefits from negative situations [28]. It might also be helpful to reassure AYAs that everyone has stress and worries and that they shouldn't be ashamed for how they feel. Normalising and validating negative feelings can encourage AYAs to be more accepting of certain stressors. Instead of exerting energy on denying their feelings and problems, this attention can be refocused on learning to thrive despite limitations by developing personal values and interests [27]. Particularly for stressors that are outside of one's immediate control, such as managing unpredictable symptoms and outcomes of RMD, this type of accommodative coping was consistently found to lower levels of anxiety and depression [29].

Psychological Needs

Resilience in AYAs can also be promoted through satisfying three innate psychological needs [21, 22]:

1. **relatedness**; the need to feel connected to and cared for by others, satisfied through building relationships that are based on mutual trust and respect.
2. **competence**; the need to experience efficacy and mastery, such as having the skill to accomplish a goal

3. **autonomy**; the need to make choices and take initiative for one's own decisions and behaviours.

Relatedness could be increased by developing an understanding and trusting relationship between AYAs and HCPs (see Chap. 4). It is important to be aware of the widespread impact of RMD on the young person's everyday life and avoid the application of adult values when assessing the impact of a potential stressor. For example, attributes affected by RMD, such as physical appearance, sexual identity, and relationships, have greater impacts on AYAs' than adults' self-esteem [30, 31], and should be recognised and taken seriously. Especially in cases where an adolescent's pubertal development is affected by their RMD or treatment, HCPs should ensure that the adolescent's sexual anxieties are addressed and not ignored. By establishing a strong AYA-HCP relationship, young people will more likely adopt active coping by seeking help and working together with the healthcare team to manage their RMD.

Another essential predictor of psychological wellbeing in AYAs is the feeling of competency or self-efficacy, which is how confident someone is in their abilities to achieve a goal [32]. Low self-efficacy creates feelings of helplessness and a tendency to avoid problems instead of adopting more positive coping techniques. One way to improve sense of competency is to establish realistic goals for treatment and management. For example, if AYAs expect to find a cure for their condition, they may develop low self-efficacy due to hopelessness. However, if the goal is more achievable, such as adapting to RMD by improving quality of life despite their symptoms, then this may enhance a sense of accomplishment and encourage better adjustment. High self-efficacy may also help AYAs reappraise the situation by viewing the stressor as a challenge and opportunity to grow instead of a threat.

Self-efficacy in other life domains are extremely valuable as well, as participation in extracurricular activities increases AYAs' wellbeing, even after controlling for disease severity [33, 34]. This is especially true for activities that provide opportunities for developing new skills and relationships.

Fostering internal qualities can reduce anxieties for some RMD-related issues by keeping their importance in perspective, such as decreasing the impact of physical appearance on self-esteem. Moreover, regular interactions with same-aged peers can help AYAs acquire social skills necessary for psychosexual development. It is thus critical to help AYAs identify, and encourage sustained participation in, hobbies such as sports and music.

In addition to feeling competent in achieving a goal, AYAs also need to have the autonomy to choose what goals to pursue and how they are achieved. HCPs can increase autonomy by integrating AYAs' needs into treatment plans and allowing AYAs to make informed decisions regarding their health. Being actively involved in the decision-making process can help AYAs develop problem-solving strategies and empower them to take ownership of their wellbeing (see Chap. 4). HCPs may also need to educate parents about the benefits of giving adolescents the freedom to participate in activities independently and of making lifestyle-related decisions. Control over treatment and lifestyle-related activities can help AYAs acquire skills needed for active coping, such as how to seek relevant information, generate possible solutions, and weigh the pros and cons of an option.

Secondary Prevention: Identifying Psychological Problems

Early Detection and Regular Screening

Even when efforts to prevent mental health problems in AYAs are an integral part of care, guilt, rage, and hopelessness can arise at various stages due to the uncertain and chronic nature of RMD. Thus, early detection and management of emotional issues are vital in preventing further deterioration and encouraging rapid recovery. However, the difficulty of distinguishing normal emotional variabilities during adolescence and young adulthood from true psychological problems can often lead to late detection, and sometimes complete disregard, of mental health issues.

Normal AYA angst is transient, confined to a single setting such as home or school, and does not cause significant impairments. In contrast, mental health disorders persist over time, with symptoms presenting in various environments, negatively impacting important areas of life, and sometimes resulting in physical symptoms such as weight fluctuations, headaches, and sleep problems [7, 8]. Additionally, AYAs who are exposed to risk factors such as academic problems, abuse, issues with peers, bereavement, and family conflict, have higher psychological vulnerabilities. HCPs should thus be vigilant in routine assessments for these stressful life events and for deteriorations in academic/work performance and relationship quality, as well as for physical symptoms not readily explained by RMD.

There is a growing interest in the use of patient-reported outcome measures (PROM) in daily practice to monitor psychological wellbeing. Regular screenings can also create a more accessible environment where AYAs feel comfortable disclosing psychological problems, even when they are seeking treatment for a physical illness (see Chap. 4). PROMs such as the Centre for Epidemiological Studies Depression Scale and the Patient Health Questionnaire are brief (<10 min), free to use, and allow for longitudinal assessments in both adolescents and adults [35, 36]. However, PROMs are not all-encompassing and AYAs may underreport negative feelings due to fear of mental health stigmatisation or by using denial as a coping strategy [37]. PROMs should therefore not substitute for thoughtful face-to-face assessments (see Chap. 4).

Management and Referrals to Psychological Therapies

Decisions for psychological referrals depend on the type of problem, duration, and severity. Emotional disorders, such as mild depression, can often remit spontaneously in AYAs and a period of "watchful waiting" whilst providing general support for adaptive coping skills can be sufficient [38]. It is essential to approach the situation sensitively by speaking with AYAs on their own before involving others, such as parents, friends, or teachers. Although help from others can

be beneficial, it is important to respect adolescents' wishes and explore with them various ways in which they can receive social support. In addition, AYAs should be signposted to youth-friendly web-based resources around issues of mental health and organisations they can contact for confidential support. Information about how and where to obtain these resources should be readily available on the centre's website or advertised in waiting areas.

If emotional problems persist and severely impair functioning, then HCPs should consider referring AYA to psychological services. In these situations, ensure that psychological support is introduced as part of the multidisciplinary approach for managing RMD, and that it will only supplement, not replace, medical support. Even if a psychological referral has been made, it is essential to continue reviewing AYAs' emotional state at each RMD appointment to reassure the young person that their psychological wellbeing is as important as their physical health.

Key Management Points

1. Encourage active and accommodative coping by recognising and modifying cognitive distortions and by increasing levels of relatedness, competence, and autonomy.
2. Acknowledge AYAs' concerns. Stressors that may seem trivial to adults could be challenging for AYAs as they value different attributes and are still developing cognitive and regulatory abilities.
3. Provide information for, and signpost them to web-based resources and support for, managing RMD and psychosocial challenges. These resources should be AYA-appropriate, reliable, and displayed in places where AYAs can easily see and access.
4. Support participation in extra-curricular activities that won't aggravate RMDs but are still enjoyable, to help AYAs develop new skills, social relationships, and a more positive outlook.

5. Ask AYAs about their opinions and preferences and help them make informed decisions about their treatments/management in order to promote autonomy and problem-solving skills.
6. Be aware of physical and behavioural changes, as well as of negative life events that AYAs are experiencing, and encourage conversations around issues of mental health to help with early detection of psychological distress.

Conclusion

Adolescence and young adulthood is an exciting and challenging phase of life, but it is also a period of heightened vulnerability. Being aware of the interplay between RMD and multifactorial sources of risks for psychological problems is central to the complete management of AYAs. Although psychological issues can be complex and difficult to manage, disregarding them can have profound, negative impacts on AYAs' current and future quality of life [5]. Acknowledgement of the importance of good psychological health should thus be the responsibility of the healthcare team as a whole. This chapter has hopefully provided practical tools to help HCPs improve psychological resilience and address AYAs' emotional needs during routine practice.

References

1. Somerville LH, Jones RM, Casey BJ. A time of change: behavioral and neural correlates of adolescent sensitivity to appetitive and aversive environmental cues. Brain Cogn. 2010;72(1):124–33. https://doi.org/10.1016/j.bandc.2009.07.003.
2. Harter S, Bresnick S, Bouchey HA, Whitesell NR. The development of multiple role-related selves during adolescence. Dev Psychopathol. 1997;9(4):835–53. https://doi.org/10.1017/S0954579497001466.

3. Esberger K. Body image. A handbook of science. Pract Prev. 2011;4. https://doi.org/10.1007/SpringerReference_223404.
4. Dillon FR, Worthington RL, Moradi B. Sexual identity as a universal process. In: Handbook of identity theory and research; 2011. p. 649–70. https://doi.org/10.1007/978-1-4419-7988-9_27.
5. Marques SC, Pais-Ribeiro JL, Lopez SJ. The role of positive psychology constructs in predicting mental health and academic achievement in children and adolescents: a two-year longitudinal study. J Happiness Stud. 2011;12(6):1049–62. https://doi.org/10.1007/s10902-010-9244-4.
6. Patton GC, Coffey C, Cappa C, et al. Health of the world's adolescents: a synthesis of internationally comparable data. Lancet (London, England). 2012;379(9826):1665–75. https://doi.org/10.1016/S0140-6736(12)60203-7.
7. Farah MJ, Noble KG, Hurt H. The developing adolescent brain in socioeconomic context. In: Adolescent psychopathology and the developing brain: integrating brain and prevention science; 2007. https://doi.org/10.1093/acprof:oso/9780195306255.003.0016.
8. Evans GW, Schamberg MA. Childhood poverty, chronic stress, and adult working memory. Proc Natl Acad Sci. 2009;106(16):6545–9. https://doi.org/10.1073/pnas.0811910106.
9. Steinberg L. Cognitive and affective development in adolescence. Trends Cogn Sci. 2005;9(2):69–74. https://doi.org/10.1016/j.tics.2004.12.005.
10. Turkel S, Pao M. Late consequences of chronic pediatric illness. Psychiatr Clin North Am. 2007;30(4):819–35. https://doi.org/10.1016/j.psc.2007.07.009.
11. Sathananthan R, David J. The adolescent with rheumatic disease. Arch Dis Child. 1997;77(4):355–8. https://doi.org/10.1136/adc.77.4.355.
12. Erkolahti RK, Ilonen T, Saarijärvi S. Self-image of adolescents with diabetes mellitus type-I and rheumatoid arthritis. Nord J Psychiatry. 2003;57(4):309–12. https://doi.org/10.1080/08039480310002101.
13. Pinquart M. Body image of children and adolescents with chronic illness: a meta-analytic comparison with healthy peers. Body Image. 2013;10(2):141–8. https://doi.org/10.1016/j.bodyim.2012.10.008.
14. Al Sabbah H, Vereecken CA, Elgar FJ, et al. Body weight dissatisfaction and communication with parents among adolescents in 24 countries: international cross-sectional survey. BMC Public Health. 2009;9:52. https://doi.org/10.1186/1471-2458-9-52.

15. Taal E, Rasker JJ, Timmers CJ. Measures of physical function and emotional well being for young adults with arthritis. J Rheumatol. 1997;24(5):994–7.
16. Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: social function, relationships and sexual activity. Rheumatology (Oxford). 2002;41(12):1440–3. https://doi.org/10.1093/rheumatology/41.12.1428.
17. Kaushansky D, Cox J, Dodson C, McNeeley M, Kumar S, Iverson E. Living a secret: disclosure among adolescents and young adults with chronic illnesses. 2016; https://doi.org/10.1177/1742395316655855.
18. Neufeld JA, Klingbeil F, Bryen DN, Silverman B, Thomas A. Adolescent sexuality and disability. Phys Med Rehabil Clin N Am. 2002;13(4):857–73. https://doi.org/10.1016/S1047-9651(02)00045-1.
19. Moore S, Rosenthal D. Sexuality in adolescence: Current trends. Hove: Routledge, 2006.
20. Berman H, Harris D, Enright R, Gilpin M, Cathers T, Bukovy G. Sexuality and the adolescent with a physical disability: understandings and misunderstandings. Issues Compr Pediatr Nurs. 1999;22(4):183–96. https://doi.org/10.1080/014608699265275.
21. Tay L, Diener E. Needs and subjective well-being around the world. J Pers Soc Psychol. 2011;101(2):354–65. https://doi.org/10.1037/a0023779.
22. Deci EL, Ryan RM. The "What" and "Why" of goal pursuits: human needs and the self-determination of behavior. Psychol Inq. 2000;11(4):227–68. https://doi.org/10.1207/S15327965PLI1104_01.
23. Compas BE, Connor-Smith JK, Saltzman H, Thomsen AH, Wadsworth ME. Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. Psychol Bull. 2001;127(1):87–127. https://doi.org/10.1037/0033-2909.127.1.87.
24. Connor-Smith JK, Compas BE, Wadsworth ME, Thomsen AH, Saltzman H. Responses to stress in adolescence: measurement of coping and involuntary stress responses. J Consult Clin Psychol. 2000;68(6):976–92. https://doi.org/10.1037//0022-006X.68.6.976.
25. Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in childhood and adolescence. Annu Rev Clin Psychol. 2012;8(1):455–80. https://doi.org/10.1146/annurev-clinpsy-032511-143108.

26. Beck JS. Cognitive behavior therapy: basics and beyond; 2011. https://doi.org/10.1017/CBO9781107415324.004.
27. Burckhardt R, Manicavasagar V, Batterham PJ, Hadzi-Pavlovic D, Shand F. Acceptance and commitment therapy universal prevention program for adolescents: a feasibility study. Child Adolesc Psychiatry Ment Health. 2017;11(1):27. https://doi.org/10.1186/s13034-017-0164-5.
28. Reinecke MA, Ryan NE, Dubois DL. Cognitive-behavioral therapy of depression and depressive symptoms during adolescence: a review and meta-analysis. J Am Acad Child Adolesc Psychiatry. 1998;37(1):26–34. https://doi.org/10.1097/00004583-199801000-00013.
29. Dufton LM, Dunn MJ, Slosky LS, Compas BE. Self-reported and laboratory-based responses to stress in children with recurrent pain and anxiety. J Pediatr Psychol. 2011;36(1):95–105. https://doi.org/10.1093/jpepsy/jsq070.
30. McDonagh JE. Young people first, juvenile idiopathic arthritis second: transitional care in rheumatology. Arthritis Rheum. 2008;59(8):1162–70. https://doi.org/10.1002/art.23928.
31. Hair EC, Jager J, Garrett SB. Helping teens develop healty social skills and relationships: What research shows about navigating adolescence. Washington, DC: Child Trends, 2002.
32. Bandura A. Recycling misconceptions of perceived self-efficacy. Cogn Ther Res. 1984;8(3):231–55. https://doi.org/10.1007/BF01172995.
33. Ennett ST, DeVellis BM, Earp JA, Kredich D, Warren RW, Wilhelm CL. Disease experience and psychosocial adjustment in children with juvenile rheumatoid arthritis: children's versus mothers' reports. J Pediatr Psychol. 1991;16(5):557–68. http://www.ncbi.nlm.nih.gov/pubmed/1744805. Accessed October 31, 2017.
34. Leversen I, Danielsen AG, Birkeland MS, Samdal O. Basic psychological need satisfaction in leisure activities and adolescents' life satisfaction. J Youth Adolesc. 2012;41(12):1588–99. https://doi.org/10.1007/s10964-012-9776-5.
35. Weissman MM, Orvaschel H, Padian N. Children's symptom and social functioning self-report scales: comparison of mothers' and children's reports. J Nerv Ment Dis. 1980;168(12):736–40. https://doi.org/10.1097/00005053-198012000-00005.
36. Faulstich ME, Carey MP, Ruggiero L, Enyart P, Gresham F. Assessment of depression in childhood and adolescence: an evaluation of the Center for Epidemiological Studies

Depression Scale for Children (CES-DC). Am J Psychiatry. 1986;143(8):1024–7. https://doi.org/10.1176/ajp.143.8.1024.

37. Phipps S, Srivastava DK. Repressive adaptation in children with cancer. Health Psychol. 1997;16(6):521–8. Cognitive therapy and research.
38. Freer M. The mental health consultation (with a young person): A toolkit for GPs [Internet]. RCGP and the Charlie Waller Trust; 2012 [cited 2018 Nov 26]. Available from: http://www.rcgp.org.uk/clinical-and-research/clinicalresources/youth-mental-health/youth-mental-health-resources.aspx.