Chapter 3
Impact of Rheumatic Disease on Social Development in Adolescents and Young Adults

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Social Development of AYA and the Influence of RMD

As discussed (see Chaps. 1 and 2), biological changes during adolescence interact with psychosocial development to set up a range of new behaviours not seen in childhood or often

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dealt with in paediatric care [1]. These biopsychosocial interactions include puberty, neurological maturation, abstract thought, self-identity, peer identification and autonomy [2]. The main factors of typical adolescent social development can be broadly categorised as 'independence', 'emotional adjustment' and 'identity formation' [3]. By late adolescence and early adulthood, several developmental tasks should be in progress or achieved [2–4]:

- Emergence of autonomous behaviour and social independence
- Intimate relationships and secure friendships
- Experimentation with personal and sexual identity
- Self-development
- Emotional skills development
- Vocational capability, including financial independence

Chronic childhood-onset conditions often disrupt young peoples' sense of normality and impair their capacity for social participation [5]. This results in delayed social maturation leading to knock-on effects into adolescence and young adulthood, as AYA with RMD can feel misunderstood and stigmatised from an early age. The physical and psychosocial challenges experienced with RMD are particularly salient and difficult for AYAs compared to children and adults, because of peer pressure to 'fit in', cultural associations between youth and health, exposure to social stigmas around disability and limited experience in adjusting to adversity [4, 6]. Some AYA with RMD can be at risk of experiencing social difficulties, due to physical and psychological effects of disease and its treatment, including disruptions and restrictions to daily life [7].

Social functioning has been ranked as a top area impacted by RMD in those aged 16–25, with this effect on their lives more important than pain/stiffness and functional impairments [8]. Table 3.1 shows the range of social impacts due to RMD, meaning opportunities available for healthy peers can be missed in AYA. These negative social consequences occur during any point of the fluctuating disease course, even during disease inactivity, as a result of affected quality of life from symptomatology not directly

Table 3.1 Effects of RMD, including disability and/or medications on typical social development in AYAs [4, 7, 9–17]

Hindered development of independence, including delayed independent living
Reduced self-esteem
Affected self-confidence and heightened self-consciousness, resulting from side effects of medications impacting body image (e.g. weight gain and hair loss)
Forced locus of control to be external, rather than internal
Less opportunities for participation in social activities and consolidation of social skills, due to impact of pain, fatigue and reduced mobility
Medication impeding daily activities, such as side effects, medication times, administration, storage or restrictions due to interactions (e.g. alcohol intake and methotrexate)
Transport issues, e.g. relying on parents for transport when friends can use public transport self-sufficiently
Feeling isolated and potentially bullied causing social anxiety, especially if experiencing long or multiple absences from school/university/work caused by ill health or healthcare utilisation
Overprotective family and/or peers imposing restrictions
Problematic relationships with friends, family and professionals
Difficulties with intimate relationships, potentially due to additional pressure or guilt of having someone be concerned and caring for you
Educational difficulties and subsequent greater problems with vocation, either in finding employment or experiencing discrimination
Struggles with identity, as misrepresented self being defined by disease
Restricted major life decisions, such as narrowed career options, threat to parenthood and/or travelling considerations
Unable to be as spontaneous or experimental as peers, with disease-related anxiety caused by unpredictability of disease and side effects of treatment

driven by inflammation [18, 19]. AYAs with RMD are often unable to achieve the same level of autonomy as healthy peers, as the shift in balance of independence is affected [2]. There can be a reliance on parents for involvement in their treatment that is either driven by the young person not feeling confident in self-management or due to parents not letting go.

Childhood illness may influence a typical child–parent interaction (see Chap. 5) and parenting styles particularly in regard to fostering autonomy and independence [9]. Parents' and close others' concerns can restrict activities and overprotect AYAs [20]. This overprotection can have detrimental effects on achieving autonomy and hindering experimentation that results in completion of social development tasks.

The main challenge for AYAs with RMD is achieving an identity not defined by their illness. This involves developing their ability to accomplish desired activities, experience positive relationships [6], manage pain, use social support and live one day at a time [10]. Otherwise AYAs can resent the restrictive impact of disease on limiting physical and social capacities, career opportunities and parenthood goals [11]. Adapting, planning and pacing activities are required to maintain social involvement and prevent additional pain and fatigue from exerting excessive energy when attempting to keep up with peers [21]. Positive emotions and self-esteem can be maintained through acceptance of their abilities and limitations. HCPs should encourage a discussion on realistic goal setting, e.g. SMART goals (Specific, Measurable, Attainable, Relevant, Time-bound). Despite the numerous barriers mentioned in this section, most AYAs with RMD are socially competent and comparable to healthy counterparts on social functioning, acceptance and behaviour [4, 7, 9], adjusting and coping quite well with the psychological and social sequelae of their RMD over time [21].

Social Aspects of Health Behaviours, Disease Course and HCP Management Strategies for AYA with RMD

During the AYA developmental stage, independent health behaviours begin and can be established as lifelong habits [22]. Adolescent social development can lead to egocentric behaviour and a disregard for the consequences of their behaviour on others [2]. This change in attitude and hindered forward planning, due to delayed neurological development (see Chap. 1), can increase risk-taking health behaviour. The extent to which typical adolescent issues affect illness management and control will depend on how AYA balances competing priorities [16]. For example, the need for social support and acceptance can tempt AYAs to give into peer pressure by undertaking exploratory behaviours [23] that can put RMD management at risk. These risky health behaviours can include chaotic, nutritionally poor eating habits, smoking, alcohol, drug use and sexual risk-taking [16].

Conversely, some AYAs report being able to use their condition or medications as a convenient excuse not to participate in behaviours they don't want to [23], with peer pressure lessened when the adverse effects were explained to peers. Treatment can be seen as both an opportunity for living a 'normal' life and also a threat to achieving this [24].

Rheumatology HCPs have the unique, ongoing opportunity to assess social, mental and emotional functioning, in addition to physical outcomes, and intervene early in a non-psychiatric environment [9, 25]. This should start once RMD diagnosis is confirmed with an initial comprehensive psychosocial assessment (see Chap. 2 for other areas to monitor). During routine clinic visits, some patients may benefit from a more unstructured opportunity to express their illness experience, but following a structured psychosocial screen such as HEEADSSS (see Chap. 4) is useful for AYA and HCP alike.

The Importance of Peer Support for AYA with RMD

Peer support through strong peer relations is vital during adolescence to promote typical social development [3, 10, 26], since friendships nurture self-development separate from familial identity. Peers offer practical, emotional and social support [17] and can facilitate adjustment to chronic disease, coping with pain/illness and adherence by reducing general and illness-related stress [23]. They can increase optimism and alleviate feelings of social isolation, which can assist the adoption of healthy behaviours, disease management skills [25] and acceptance of help with disease management [27]. Conversely problematic unsupportive relationships lead to increased distress and disease activity [26, 28], by being oppressive, underestimating the disease and not providing useful advice [29]. Regardless of social network size, AYA primarily discloses their illness to family members and only to a few peers.

Good support from peers is key to adjustment, whereas support from the wider network (e.g. teachers, employers and nurses) becomes more important when family functioning is less positive [27]. Reasons for withholding and not seeking support can include fear of rejection, pity, perceptions of being seen as vulnerable or different, dismissal of their problems/concerns as unimportant or alternatively overreactions and limiting of social activities/involvement. Sometimes others do not perceive these AYAs as chronically ill [7] in part due to the fluctuating and invisible nature of disease or not understanding the emotional impact of coping with daily pain and taking medications [25]. Disclosure can be influenced by [26, 30]:

- Perceived trust and familiarity
- Shared experience with illness/disability
- Visibility of the condition and practical needs
- Recipient's anticipated response
- Decision that disclosure is justified

It is important that appropriate information regarding RMD, and the specific impact it has on that young person including pain and mood, is shared with peers, school and work to enable appropriate support [25, 31]. Greater support beyond educational attainment is needed [12, 13], such as focusing on finding and keeping employment. AYAs and parents can be supported to disclose information in an appropriate and stepwise manner depending on their preferences and needs. For example, with the YPs' consent, the school nurse or university doctor should be fully notified, whereas teachers or employers could be given information on supporting the young person during absences or coping with critical events [16, 25]. The healthcare team are in a position of authority and can facilitate this disclosure by examining how the organisation (school, university or work) and the content of the treatment can be modified according to the AYA's lifestyle, suggesting dialogue for the young person to say or providing supporting clinical letters of recommendation to schools or local authorities.

Peer support from other AYAs with similar RMDs can provide meaningful emotional and social support due to a shared understanding of living with a chronic unpredictable disease, reducing isolation and negating the problems in support from friends without a RMD diagnosis [32]. This support can involve discussions around acknowledging and overcoming concerns for the future (education, occupation or relationships), strategies around taking medication and developing positive lifestyles in terms of physical activity and psychological wellbeing through goal setting and action planning [33]. This can be disease specific or regarding areas indirectly impacted such as school/work and social life. Support groups, peer mentorship, residential weekends and virtual forums provide opportunities for peer networking, sharing inner thoughts to strengthen self-development and self-management confidence [10, 17, 32]. Moreover, many AYAs are more open to recommendations from near-peer mentors versus adult mentors or professionals and may see other young adults coping successfully with a similar diagnosis as a sign of hope, which increases motivation and confidence that they too can manage their illness [32].

Summary

It is extremely positive that many AYAs are doing well with regard to psychosocial adjustment and are comparable to peers in several areas. However those at risk need to be identified and intervention measures introduced as early as possible [7, 9], as impact on behaviour and management of disease can still be profound. Therefore regular screening/discussions to assess the psychosocial burden impacting quality of life are important to personalise treatment [28]. It is imperative to match the needs and preferences of the young person with the support provided [26], with HCPs providing a flexible and youth-friendly approach.

Key Management Points

- Explore social functioning and support, screen for social issues and identify areas needing support and appropriate referral, e.g. nurse or psychologist:
  - Follow HEEADSSS psychosocial interview [34] to assess social issues and changes to a patient's social situations that might impact wellbeing.
  - Use brief screening questionnaires in clinic such as the Work and Social Adjustment Scale [35] to quickly assess impact of illness on functioning by assessing work, home management, leisure activities and family/relationships, to highlight areas needing discussion and support.
  - Allow time for unstructured discussion, and encourage questions to gain further understanding of their perceptions of impact and distress.
  - Decide whether to escalate beyond patient education and whether to refer to psychology, particularly if disease is active or severe.

- Ensure the young person has routine access to a key worker (such as a clinical nurse specialist, special educational need co-ordinator or social worker), to develop appropriate education, health and care plans to support continued engagement with activities and/or return to school or work.
- Signpost AYAs to further information and support from charities and other organisations for general information about living with RMD and further resources and support.
- Enable peer-to-peer support with other AYAs with RMD, and help the young person make connections through charities and organisations.
- Encourage parents, family members and/or partners to be supportive in helping the young person gain independence and social contacts in line with typical AYA social development.
- Engage AYAs in shared decision-making regarding treatment options, including seeing the young person alone for a portion of the consultation, to encourage independence from parents and promote self-management.

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