Chapter 5

Adolescents, Young Adults and Their Parents

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Introduction

Although the concept of family has evolved over time, there is evidence that parents remain their child's first role model. Parenting involves the care and guidance that enable young people to grow, develop and make appropriate choices. In recent years, there has been an increasing interest in promoting parental involvement in the lives of Adolescents and

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Young Adults within a resilience perspective. Tips for parents in the process of raising adolescents have been developed by several authors to address these resilience factors. When appropriate, some of them can be used in the clinical setting in order to facilitate parental adaptation to this life cycle stage and to their AYA living with a RMD (Table 5.1) [1].

TABLE 5.1 Ten golden rules for parents raising adolescents

Ten top tips for parents of adolescents
1. Listen to your adolescent. Always be available to talk and listen.
2. Be kind. Don't be inhibited when showing affection, provided that you do not embarrass your adolescent before friends.
3. Get involved in your adolescent's life and follow his/her academic performance. Your involvement is as important if not more so than during childhood.
4. Make an effort to get to know your adolescent's friends. That is the only way you can have to better understand his/her behavior.
5. Be firm. Set up limits and establish clear and adequate rules.
6. Avoid too much control and don't be too bossy. Autonomy is essential for an adolescent to grow up well. Provide him/her with enough room to learn how to be self-confident and to make decisions without looking for your constant advice.
7. Guide your adolescent on the most difficult decisions. He/she may not be ready or mature enough to plan, set up priorities, organize thoughts, manage impulses, and/or be thoughtful about every consequence of his/her own actions.
8. Have positive and realistic expectations about your adolescent. But be realistic: your expectations should be neither too high nor too low.
9. Help your adolescent to become a sensible and responsible citizen. Help him/her to improve his/her respect for everyone, regardless of race, gender, status, or religion.
10. Love your adolescent unconditionally.

Adapted from Fonseca [1]

Steinberg defined four main styles of parenting: authoritative (warm and firm); authoritarian (firm but not warm); indulgent (warm but not firm); and neglectful (neither warm nor firm). He found that AYA raised in authoritative households are more psychosocially competent, more successful in school, and less prone to internalizing or externalizing problems than their peers who have been raised in other styles [2]. AYA with RMD are no exception and their parents have to deal not only with the normal developmental challenges of adolescence (see Chaps. 1, 2 and 3) but also with their AYA's chronic condition.

RMD has a significant impact on families because the ongoing care and management rests primarily with the AYA and their family [3]. Many healthcare professionals and especially adult providers have not been sufficiently trained to assess the developmental and psychosocial challenges faced by AYA and their families with chronic conditions. The Family Adjustment and Adaptation Response Model developed by McCubbin and Patterson [4] is especially useful for examining the impact of the condition on the family as well as which resources and coping behaviors inside the family may facilitate a successful adaptation of the family unit to AYA with RMD. Throughout the life cycle of the family, the unit (like all social systems) attempts to maintain balanced functioning by using its capabilities (resources and coping behaviors) to meet its demands (stressors and strains). The seriousness and chronicity of the AYA's illness will influence the intensity of the demand and how much it interferes with the family's homeostatic state.

A variety of theoretical models dealing with a systems perspective on the family have been developed. Olson's circumplex model was developed as an attempt to bridge the gap between theory and practice. It is basically based in two dimensions (adaptability and cohesion) with a third dimension (communication) considered as a facilitating dimension [5].

- **Cohesion** is the emotional bonding that family members have toward one another. Four levels of cohesion have been defined, ranging from disengaged (very low) to enmeshed (very high) with both of these extreme levels potentially being problematic.

  Optimal functioning, comprising ‘low to moderate’ (separated) and ‘moderate to high’ (connected) levels of cohesion, means achieving a balance of togetherness and separateness. Family members are connected yet separate. The hypothesis is that too much or too little cohesion will lead to problems in the long term.

- **Adaptability/flexibility** is the ability of the family system to change in response to situational and developmental stresses. The rigid dominant pattern of family functioning is characterized by a very low level of adaptability, authoritarian leadership, with roles seldom changing, strict discipline and too little change. In the other extreme, the chaotic dominant pattern is characterized by lack of leadership, dramatic role shifts, erratic discipline, too much change. Structured and flexible levels of adaptability are those at the center, more conductive to healthy family functioning.

  Optimal family functioning involves a balance of stability and change. Both are necessary.
- **Communication** is the third dimension, which facilitates a family’s ability to change its levels of cohesion or flexibility. The hypothesis is that communication skills make it possible for families to change in response to situational stressors and developmental transitions.

The model serves as a typology to distinguish different types of families, falling into three categories: (i) balanced; (ii) midrange; and (iii) extreme or unbalanced, as follows:

(i) Types of balanced families: flexibly connected, flexibly cohesive, structurally connected, and structurally cohesive.
(ii) Types of midrange families that are balanced on one dimension and extreme on the other. The types are chaotically connected, chaotically cohesive, flexibly enmeshed, structurally enmeshed, rigidly cohesive, rigidly connected, structurally disengaged, and flexibly disengaged.
(iii) Types of extreme or unbalanced families: chaotically disengaged, chaotically enmeshed, rigidly enmeshed, and rigidly disengaged.

A double balance of togetherness/separateness and of stability/change, portray the most protective scenario. Extreme levels of family functioning, were associated with poor medication adherence, for example, in the treatment of juvenile arthritis [6], which is consistent with the findings concerning families with children who live with other conditions, such as diabetes.

Family dynamics highly influence the way AYA with RMD and their parents interact, with a significant impact on the AYA autonomy and identity construct.

There is a wide spectrum of family typologies (traditional, single, divorced, reconstructed, same-sex), coming from different cultures and backgrounds. The roles of their caregivers, however, do not differ much. A combination of a warm and firm (being able to set limits and define rules in a consistent way) style of parenting; a family functioning balanced between stability and change, togetherness and separateness, are key components of a successful parenting in all sorts of families and irrespective of having a AYA living with a chronic condition.

Case Report 1

DS, currently 21 years old, presented at age 15 with systemic lupus erythematosus (SLE) and lupus nephritis treated with corticosteroids, hydroxychloroquine, mycophenolate mofetil and enalapril with good effect. At age 17 DS became depressed, addicted to computer games and had progressive weight gain. He was in denial and began missing his treatment. He was an only child living alone with his mother (his father with alcohol dependence was living abroad). His mother, was always very supportive and concerned, but felt she had no control over him. DS lost 1 year at school and had a relapse of his SLE with cerebral vasculitis. The depression worsened, and he had suicidal ideation. He was treated with cyclophosphamide and antidepressants with good adherence this time, as he became scared about the severity of his SLE.

The transition process to adult care had been initiated 2 years before but delayed until the disease was controlled. Currently, he is proceeding with his studies, never misses a clinical appointment, comes by himself and has good adherence to treatment.

The psychosocial impact of SLE on an adolescent like DS is significant (see Chaps. 1, 2, 3 and 8). His personal and family history, deeply influenced his experience. When he first came to the Clinic his mother was feeling alone, despaired, concerned about DS lack of a male role model and clearly asking for external support. DS was at risk of dropping out from health care and he ultimately shared with us that he was fed up with having to come to the Clinic so often, as well as with his mum controlling him all the time. Although the tension between them was high and communication quite difficult, he readily identified his mother as the "trusted and significant other" in his life, feeling a strong sense of support from her and perceived she was someone with whom he could share his problems.

For the team managing DS, risk factors were seen to outweigh protective factors in his life, so they decided to reinforce the protective factors by providing support, relationships, experiences, and opportunities to promote positive outcomes.

The team acknowledged the mother's difficulty in allowing her son to take control of his own healthcare management, and in facilitating his autonomy to negotiate treatment plans. A family intervention was started based on:

- supporting DS and his mother in clarifying their respective demands
- modulation of empathy towards DS and his mum
- raising questions in a non-judgemental and open way
- enabling and empowering each of them to express themselves.

DS and his mother benefited from a patient and family centered care treatment plan, acknowledging that a progressive transition from parental management to self-management should happen throughout adolescence.

Because communication was difficult/damaged, some systemic therapy techniques were applied:

(i) Neutrality: health professional's neutrality has to be preserved at all cost, by challenging everyone and everything while siding with no one.
(ii) Turn-taking: involving each family member in turn, avoiding questions that invite yes/no responses, checking back with each participant and ask how they see something that others have commented on.
(iii) Circular questioning to see clearly what the definition of the problem is for each family member; for example *"What do you think X will say the problem is? … Who agrees with him? … Who disagrees? … How would you put it? … In what way is this problem a problem? … What makes the problem a problem? … How is it a problem for you? … Who is it most a problem for?"*
(iv) Problem solving: by asking each member *"If you could change one thing … what would it be?"*, negotiation can be facilitated. Ideally, the adolescent/family create the solution, but if not, the health professional can make a proposal for discussion.

Case Report 2

JG, a 12 year old girl was diagnosed with polyarticular Juvenile Idiopathic Arthritis (JIA), and treated with methotrexate with a very good response. She experienced nausea on the day of her methotrexate injection and started refusing treatment at 13 years of age. The arthritis got worse and her life at school became quite difficult. Her teachers were asked to give her extra time for work, but her classmates did not understand this allowance and started bullying her. She lived with her parents and with her younger brother and sister. Her parents were very engaged in helping her cope with treatment. They invited friends over on the day of the injection and this positive distraction worked well with no more resistance to treatment and complete remission one year later.

At school JG was asked to tell a story to the class and her parents encouraged her to present the story of an adolescent with JIA. Her classmates were very understanding, and the bullying stopped. She is now 15 years old, doing very well at school and in complete remission with a very good knowledge about her condition and management.

JG's family style of parenting could be defined as authoritative and her parents were quite involved and warm, but simultaneously able to set rules and define limits. The family was characterized by moderate to high levels of cohesion, and positive communication skills, including empathy, reflective listening, supportive interaction, maximizing the ability of family members to share their feelings with high levels of adaptability. They were able to facilitate the process of adherence to treatment such as inviting friends over and helping JG develop coping strategies. Family interaction with the school was crucial for a better understanding of the impact of JIA on her ability to partake in education and involvement with peers.

Parents often lack support in the difficult and complex task of supporting their AYA living with RMD as well as going through their own transition of relative detachment. Unmet parental needs include lack of tools to deal with difficulties related to autonomy and issues around relative attribution to disease versus normal adolescent development (e.g. parents of AYA with RMD suffering from psychosocial difficulties may be more inclined to relate these problems to their RMD) [7].

The struggle for autonomy can be stressful both for AYA and their parents and may be exacerbated by the limits implied by their RMD, and the specific medical care while longing for normality comparable to that of their peers [8].

Parents experiencing high levels of anxiety concerning 'letting go', tend to overprotect their AYA, making the road to autonomy more difficult to travel. This should be identified and supported by healthcare professionals. Peer-to-peer support should be considered for parents and in more severe cases referral to psychology services should take place [9].

In summary, AYA living with RMD should be viewed as any other AYA in the context of their parent relationships, acknowledging not only that they change during the course of adolescence and young adulthood but also the potential impact of RMD on these relationships.

Key Management Points

1. There is evidence that being raised in authoritative (warm and firm) households, leads to more psychosocially competent AYA, less prone to internalizing or externalizing problems.
2. Optimal family functioning involves a balance of stability and change, as well as a balance of togetherness and separateness. Both are necessary.
3. Parenting interventions are an unmet need and should address medical, psychosocial and vocational needs.
4. Parents could benefit from peer-parent support groups to better support the autonomy development of their AYA and facilitate the inclusion of parents' personal experiences in the proposed plans.

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