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## VIEWPOINT

# Person-focused care for young people with rheumatic and musculoskeletal diseases: young rheumatologists' and EULAR Young PARE perspectives

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## ABSTRACT

In recent years, the evolution of healthcare challenged the management of people with rheumatic and musculoskeletal diseases (RMDs). From disease-centred care to person-focused care, a holistic approach along with patient empowerment about their disease, improved the physician-patient relationship and allowed to achieve better outcomes with lower healthcare costs. Nevertheless, RMDs may occur from childhood to the old age and to date very few studies have addressed the needs and priorities of young people with RMDs. However, the image of RMDs is still associated with the elderly population. In this regard, the group of young people with arthritis and rheumatism in Europe (PARE) was recently developed within European League Against Rheumatism to represent the voice of the young affected and to carry out projects aiming for a better understanding of these specific aspects. This viewpoint discusses the needs and priorities of young people compared with adult people with RMDs, based on the available literature and on the results of the PARE Youth research project, aiming to identify the next steps of actions that need to be taken to improve the current situation.

## INTRODUCTION

Over the last decade, the attention of the scientific community dealing with rheumatic and musculoskeletal diseases (RMDs) has been drawn on the importance of incorporating the patient's perspective in disease-related decisions.<sup>1</sup> The active engagement of patients, their education about their disease, their empowerment aimed at optimising self-management, eventually leads to better clinical outcomes and reduction of healthcare costs.<sup>2</sup> The European League Against Rheumatism (EULAR) has fully embraced the importance of involving patients since the European organisation of people with arthritis/rheumatism (PARE) constitutes one of the three pillars of EULAR ([www.eular.org](http://www.eular.org)).

Although patient empowerment is an important step towards the optimisation of patient management, a crucial issue is the impact of the patient's age. RMDs may occur from childhood through to old age but to date very few studies have addressed the needs and priorities of young people with RMDs and there is no agreement across European countries on the definition of a 'young patient'. To date, published data concerning the specific needs of young people with RMDs are lacking as studies specifically addressing this topic are very few. Furthermore, it has never been explored whether the needs and priorities of young people with RMDs who were diagnosed in paediatric age and those who were diagnosed between 18 and 35 years of age differ. Over the last few years, PARE has been working towards making the voice of young patients heard and this led to the birth of a working group called Young PARE.<sup>5</sup> Young PARE consists of people aged 18–35 years affected by RMDs (either diagnosed within this age range or in paediatric age). In parallel, the PARE Youth research project was developed to gather a large amount of information about youth organisations in EULAR countries and explore the views, needs and priorities of young people with RMDs through a mapping exercise and a European-wide survey.<sup>6</sup>

In fact, only through understanding the similarities and differences of how RMDs impact on the life of young people compared with adult people it is possible to tailor and individualise the management of the disease in this subgroup of patients. The objective of this viewpoint is to discuss the needs and priorities of young people compared with adult people with RMDs, based on a literature



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### Box 1 Examples of responses from the PARE Youth research project

- ▶ I don't know if it is possible to 100% accept that it is happening to me.
- ▶ I am mentally trying to get used to the idea that things might go differently of what I expected for the rest of my life.
- ▶ In itself, the care from the hospital is good, but mainly focused on drugs. They take study or social life not really into account.
- ▶ Some people find it very frustrating if they cannot go to every party, I'm lucky if I can go to one.
- ▶ I got pregnant, but the doctor did not tell me that with my medication it is not allowed and I did not know to ask. I lost this chance.
- ▶ My first son was born deaf and my in-laws blamed my pharmacological treatment for their grandson's disability. I was deeply hurt by this and felt very guilty for a long time even though I stopped all medication three months prior to his conception.
- ▶ In university some professors did not believe [that I was sick] and said that young people don't have this kind of disease.
- ▶ I noticed at first that colleagues said things behind my back, for example if I called in sick.
- ▶ The feeling of doubt that you get from other people—teachers, friends, doctors, is a big barrier that can make you cautious and closed.
- ▶ When I talk to other people, they only react how horrible it is. It is very different who you talk about it. In the (patient) association I understand them and they understand me.

review and the results of the PARE Youth research project and identify actions to be taken to improve the current situation.

### HOW RMDs AND THEIR TREATMENT IMPACT THE LIVES OF YOUNG PEOPLE?

For a better understanding on how the findings were gathered by the PARE Youth project, we introduce its structure: the mapping exercise aimed at exploring the organisation of youth groups in European countries, the qualitative interviews and focus groups aimed at understanding the life domains most affected in young people with RMDs. Based on this, a survey was developed and distributed among young patients in European countries. The data of 2329 respondents, aged 18–35 years, affected by at least one RMD, were analysed. **Box 1** includes representative sentences related to the different domains collected from patients during the qualitative study.

#### Social and sexual life, mental health

A major concern of young people with RMDs is that they will not be accepted as full members of the society.<sup>6</sup> This feeling results from the fear of not being able to achieve set goals or keep control of their lives due to the unforeseeable evolution of the disease. Pain and fatigue represent the main obstacles in daily life, particularly for work ability and participation in social activities.<sup>6</sup> Besides these, one issue that infrequently assessed in clinical care when dealing with either adult or young

patients is the impact of RMDs on sexual life. In both groups, about 70%–80% of subjects report having problems due to their condition, whereby women's sexual life is more affected than that of men.<sup>6,7</sup> In this regard, the main concerns raised by young patients are pain/discomfort, fatigue, lack of sexual interest or desire and perceptions of their body being unattractive.<sup>6</sup> Conversely, in adult patients the impairment of mental health is the main determinant of sexual dysfunction and interestingly other physiological factors that affect sexual function in the general adult population such as obesity, history of cardiovascular events, smoking and alcohol consumption do not play any additional role in people with RMDs.<sup>7,8</sup> The shortcoming of information on pregnancy and especially on postnatal care further increases the fear of young women about having a successful pregnancy or being good mothers due to their disease.<sup>9</sup> In this regard, a milestone has been set by the recent release of the first EULAR recommendations on women's health for the management of family planning, assisted reproduction, pregnancy and menopause in patients with systemic lupus erythematosus and antiphospholipid syndrome.<sup>10</sup> These recommendations aim at providing the best care and appropriate counselling during the entire life span of females with this disease.

The PARE Youth report highlighted another remarkable discrepancy, namely that >90% of patients reported that their RMD had an impact also on their mental health, but only 17% of them sought psychological support. Data from adult patients reveal that only about 30%–60% of subjects report that the disease affects their mental health,<sup>7,11,12</sup> which further suggests that the burden of psychological impact of RMDs is more pronounced in young patients, necessitating prompt intervention. Living 'a normal life' has the highest priority for young people and the prescription of therapy as well as even minor modifications of the ongoing therapy can cause anxiety in young people if they are not fully aware of short-term and long-term effects of treatment.<sup>13</sup> In this regard, it is necessary to provide patients with all relevant information about the implications and possible consequences of taking or not taking their treatment, in order to maximise treatment adherence, and offer them the opportunity for discussion at every consultation.<sup>14</sup>

#### Transition from the paediatric to the adult age

Optimal medication use lies in acknowledging the roles of personal and social identities, especially including the identity transformation, before the diagnosis to develop a new social identity after diagnosis. Such new identity is itself subject to changes over time as for instance in the transition phase from the paediatric to the adult healthcare system. The 'significant others', mainly mothers, play an important role in this process, whereby parents and young patients often show discrepant priorities.<sup>14–16</sup> Ideally, the transition should be a purposeful, organised and coordinated process involving the young, their family and the healthcare team, with the goal of

optimising health, preventing morbidity and facilitating personal development. However, data from a recent European-wide survey among paediatric rheumatologists pointed out that currently one in two up to half of young subjects do not experience a successful transfer to adult rheumatology, which exposes them to unfavourable outcomes.<sup>17 18</sup> Many barriers for an effective and high-quality transition process have been identified with the most important being the assumption that transition merely means transferring the young person from a physician to another without any empowerment of the patient or their family.<sup>19</sup> From the patient's point of view, a large metasynthesis study, of all relevant studies enrolling young people with chronic diseases including RMDs, revealed that the transition phase is perceived from patients like being 'in limbo' between different cultures. The change in significant relationships, the transition to a new and unknown environment, the readiness to change independently of age and the shift of disease 'ownership' to the young person were identified as the four main themes in this transition process.<sup>20</sup> We observe with delight that this process of transition is becoming increasingly recognised as an important area for clinicians, researchers and policy makers to address.<sup>21</sup>

EULAR Young PARE is actively working to overcome these barriers and to ensure that patient associations are an active part of the transition process, providing patients in paediatric age all the support needed in this phase and ensuring their engagement within youth associations. In fact, it is recognised that the process of patient empowerment for the transition phase should start as early as possible to make sure that young people are ready when it comes to the actual transition into adult care. In this regard, a pioneering initiative to be used across specialties and applied to patients aged 11+ with a long-term condition was developed by the National Health Service in the UK. The 'Ready Steady Go' initiative is based on the use of questionnaires covering different aspects relating to the disease and the transition phase; it starts at 11 years of age and ends after the first consultation in the adult care system. By the end of the 'Go' stage, the young people should have the confidence and ability to undertake the whole clinic consultation on their own.<sup>19</sup>

In addition, EULAR and the Paediatric Rheumatology European Society recently developed the standards and recommendations for the transition of young people with RMDs diagnosed in paediatric age.<sup>22</sup> Although these recommendations set another milestone in the health-care of young people with RMDs, the authors themselves acknowledge the objective difficulty in implementing them in clinical practice across different countries. Furthermore, several questions remain pending and the research agenda for the future includes a number of points to address, including the importance of outcome measures and predictors of successful transition.<sup>22</sup>

### Study and work ability

In terms of education and work ability, RMDs cause either delay or fewer opportunities in the school career and may be a major reason to quit a paid job. There is not enough understanding and awareness on this issue among teachers, educationalists and employers. In addition, the consistent heterogeneity of social policies for patient advocacy in different countries raises the issue of lack of uniform guidelines at European level to ensure harmonisation of patient care across countries. If the social environment of people with RMDs is not appropriately informed about the disease, the interaction between the sick student and the teachers/schoolmates is heavily affected and the course of study is slowed down.<sup>23</sup> In a working environment, young people as well as adult people with RMDs fear that employers might think that they are not able to accomplish the same as healthy coworkers. This is mirrored by the reluctance to reveal their condition during interviews for a new job and not even after being hired.<sup>6 24</sup> However, it is often necessary to disclose the disease to explain frequent absences from work, although this remains uneasy for patients of any age.

Patient organisations, aside from providing supportive environments for patients, have proved to be a useful resource of information, advice and education about self-management of the disease. They play a crucial role in helping people to better understand and cope with their RMDs, for example, providing virtual communities and access to social media.<sup>25</sup> The engagement of patients on social media platforms as well as increasing availability of dedicated medical mobile applications is particularly useful for young people who are more familiar and confident with this kind of 'cyber-world'. Self-monitoring of the disease on a regular basis, easy access to health-care-related reliable information as well as contact with people of the same age affected with RMDs supports young patients in better understanding their condition, enabling interaction between them and encouraging communication and sharing of experiences. This is also valuable in reducing isolation and silent suffering potentially resulting in poor psychological consequences. Within patient organisations, the recognition that young people with RMDs have different needs and priorities compared with adults, resulted in the development of young patient organisations. Such an example at an international level is the EULAR Young PARE raised within the EULAR Standing Committee of PARE, which represents 36 European national patient organisations. The EULAR Young PARE group aims to improve the quality of life of young people with RMDs by raising the profile of these conditions, and by creating a network of individuals who work in European countries on behalf of young people with RMDs.<sup>5</sup> Beyond that, patient organisations play an increasingly prominent role also in the conduction of research. In modern rheumatology practice, providing links/contact with patient organisations along with a multidisciplinary team input (including the

physician, healthcare practitioner(s) and carers/family) represents an integral part of patient management.

### THE PHYSICIAN-PATIENT RELATIONSHIP IN 2017

The engagement of young patients in disease-related decisions implies that the relationship with the physician is based on mutual trust and that patients are informed and educated about their disease. This would not be possible without the evolution and revolution that took place over the last few years in healthcare with regard to patient engagement in the development of recommendations for disease management,<sup>11 26</sup> patient empowerment for disease-related decisions<sup>1</sup> and access to e-health resources.<sup>27</sup> The doctor-patient relationship has evolved over time from the paternalistic approach characterising the disease-centred care to the equality of the patient-centred care and person-focused care where the role of patients has shifted from being passive recipients to active participants responsible for the management of their disease.<sup>28</sup> In fact, the pillar of patient-centred and person-focused care is a shared approach in decision making, where clinicians and patients jointly and actively participate in health decisions after discussing the options, benefits and harms, while considering the patient's values, preferences and circumstances. The holistic approach of person-focused care mainly aims at targeting the illness, as defined by the unique experience of being unwell rather than the disease as defined by the mere pathophysiological process. Therefore, person-focused care also takes the age of patients at disease onset into account, to recognise different needs and priorities and it acknowledges that young patients are part of a familiar/personal network that should be integrated rather than replaced by the clinical network (physicians and health professionals). In this setting, a key event was the introduction of patient-reported outcomes (PROs) in research and clinical practice. PROs represent an essential tool to monitor the impact of the disease on quality of life and to further reach mutual treatment decisions between patients and physicians.<sup>29 30</sup> However, patients still use tools developed by physicians to report on their conditions and the scores again are evaluated by physicians, who further decide about the implications and consequences.<sup>31 32</sup> In addition, several studies clearly demonstrate that the physicians' and patients' perspectives on disease activity differ.<sup>33 34</sup> One of the most frequently reported PROs, the patient global assessment (PtGA) deviates in many cases significantly from the evaluator global assessment (EGA).<sup>35–37</sup> Pain seems to be the strongest determinant of the PtGA and the number of swollen joints, of the EGA. These discrepancies between physician and patient assessment have perhaps the greatest impact on the treatment and evaluation of outcomes. In addition, currently available PROs like the Health Assessment Questionnaire or the Short Form 36 may not capture all that matters to patients, particularly for those younger

at age, since their perspective on currently used PROs has not been explored.

### FUTURE PERSPECTIVES AND CONCLUDING REMARKS

Several forward steps have been made to develop a trustful and equal relationship between patients and physicians but it must be recognised that still many of the needs of young people with RMDs remain unmet. We acknowledge that additional studies aimed at exploring the views, perspectives and needs of young people with RMDs will shed additional light on this topic and provide the basis to tailor healthcare strategies accordingly. As far as daily clinical practice is concerned, our first recommendation for physicians is to always ask patients about the impact of their disease on them and their life rather than trying to guess their thoughts; to carefully listen to them and try to understand different perspectives according to their age, taking this into account in any disease-related decisions made. Additionally, physicians should always aim to set up a pleasant and informal environment during consultation, where patients feel comfortable to discuss and raise any concerns—also on very personal topics—they might have. Physicians should provide patients with any information they need to take decisions and to make sure that although significant others (eg, relatives, partners) tend to be prominent during consultation, the opinion of the young patient is always taken into account. Communication between physicians and patients in between consultations should be encouraged to strengthen their relationship over time. However, any contact through interactive media is an option to be considered but should always be used conscientiously, balancing the readiness of such tools with the need of personal interaction and privacy issues. Finally, in the 19th century Sir William Osler already made the point that 'the good physician treats the disease and the great physician treats the patient who has the disease', but nowadays we believe that the best physician is the keystone of the clinical and familiar networks that manages the illness experienced by the patient over time. Looking into the future, we envisage that the increasing involvement of young patients in research projects, treatment recommendations and specific PROs development and adaptations as well as the fostering of e-health are all important in bridging these gaps.

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