

Transitional care of young people with juvenile idiopathic arthritis in Italy: results of a Delphi consensus survey

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Abstract

Objective

To present the results of a Delphi consensus survey among Italian paediatric and adult rheumatologists on transitional care (TC) of young people (YP) with juvenile idiopathic arthritis (JIA).

Methods

A taskforce of 27 paediatric and adult rheumatologists evaluated the applicability of the 2016 EULAR/PreS recommendations for TC to the Italian rheumatology practice and healthcare system and formulated additional country-specific statements aimed to increase their suitability. After a two-round discussion, applicability of EULAR/PreS recommendations and agreement with newly-proposed statements were voted on a 0–10 scale (where 0 = no applicability/agreement and 10 = total applicability/agreement). A mean level of agreement ≥ 8 was deemed acceptable.

Results

The consensus threshold was reached for only 4 of the 12 EULAR/PreS recommendations and for 25 of the 27 country-specific statements. Poor agreement with EULAR/PreS recommendations was mostly explained by paucity of centres in Italy that possess both paediatric and adult rheumatologists, disagreement about optimal time of transition start and definition of transition coordinator, diversity between paediatric and adult clinimetric assessments, and lack of administrative and financial support.

Conclusion

This consensus initiative represents an important step forward toward the establishment of a nationwide TC network for YP with JIA in Italy. The main goals established for the future are the identification of adult rheumatology centres that are willing to participate in the TC process, the education of adult rheumatology teams on childhood-onset rheumatic diseases and transition issues, and the increased awareness of public healthcare authorities and other stakeholders about the importance of good-quality TC.

Key words

juvenile idiopathic arthritis, paediatric rheumatic diseases, Delphi survey, recommendations, transitional care, young people

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Introduction

The term juvenile idiopathic arthritis (JIA) describes a clinically heterogeneous group of chronic arthritides of unknown aetiology with onset before the age of 16 years (1). It is the most common rheumatic disease in childhood and a leading cause of acquired physical disability in the paediatric age group (2). Although functional outcomes have markedly improved in the past two decades, the long-term physical, psychological and socioeconomic burden of JIA is still substantial. Studies in young adults have shown that this disease is associated with significant morbidity, restricted participation in social activities and higher unemployment rate (3-5).

Many children with JIA (currently an estimated half) have persistent active disease into adulthood or develop disease flares as adults, and most of them still require anti-rheumatic therapy (5-9). These patients need continued care in adult rheumatology centres in order to receive adequate monitoring and appropriate therapy. Thus, a correct transition from the paediatric to the adult rheumatology team is fundamental to ensure that young people (YP) with JIA receive continuous and developmentally appropriate care after adolescence and achieve optimal functioning in adulthood. However, literature data indicate that nowadays up to 50% of YP with rheumatic disease do not make a proper transfer to adult rheumatology care and are, therefore, at high risk of poor outcomes (5, 10).

Transitional care (TC) has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system" (11). It is a multidimensional and dynamic process that must be age and developmentally appropriate and should ensure that the medical, psychosocial, educational and vocational needs of adolescents are met as they move from child- to adult-centered services (8, 12, 13). More in general, TC aims to provide education, support and guidance to YP in order to prepare them to become independent, empowered and responsible adults (14-

16). This goal should comprise the acquirement of the skills and knowledge necessary to independently manage their chronic illness.

Recently, an international taskforce including patients and representatives from multidisciplinary teams in adult and paediatric rheumatology issued recommendations and standards for the TC of YP with juvenile-onset rheumatic and musculoskeletal diseases, under the umbrella of both the European League Against Rheumatism (EULAR) and the Paediatric Rheumatology European Society (PREs) (14). Based on the combination of available evidence and expert opinion, 12 recommendations were formulated, which are intended to be used to guide service development, benchmark the quality of transition services and enhance patient expectation of care through their dissemination by patient organisations. As acknowledged by the taskforce, although the recommendations are thought to be widely applicable, their implementation should account for the differences in healthcare systems and regulatory bodies across countries.

Recently, a taskforce of Italian paediatric and adult rheumatologists with expertise in JIA, adult chronic inflammatory arthritis, and TC was convened to analyse the EULAR/PReS recommendations (14) and evaluate their applicability and suitability to the Italian rheumatology practice and healthcare system. To facilitate the implementation of the recommendations in the Italian environment, the taskforce formulated additional country-specific statements. The applicability of each EULAR/PReS recommendation in Italy and the validity of newly proposed statements were voted through a modified two-round Delphi method to reach consensus.

The purpose of the present paper is to present the results of this Italian consensus survey on the TC of YP with JIA.

Methods

The modified Delphi process employed in this study was conducted in the following 3 steps: 1) analysis of EULAR/PReS recommendations and formula-

tion of additional statements aimed to improve their applicability to the Italian rheumatology practice and health care system; 2) online voting of applicability of EULAR/PreS recommendations and agreement with the additional country-specific statements; 3) evaluation, rewording and re-voting of the statements that did not achieve consensus.

The steering committee of the study was composed of two paediatric rheumatologists (AR and RCi) and two adult rheumatologists (RCa and LS), selected on the basis of publication records and previous participation in similar activities. The steering committee then invited a taskforce of both paediatric (n=12) and adult (n=11) rheumatologists from all over the country (to represent possible differences in practice between regions) to take part in the study. These invitations were a consequence of the individuals' contributions to the field and deliberations among members of the steering committee.

In the first face-to-face meeting, which took place in Rome on July 20, 2017, 4 breakout groups were formed. Each group examined and discussed 4 of the 12 EULAR/PreS recommendations. For each recommendation, participants identified the problems and critical issues that could hamper its applicability to the Italian rheumatology practice and healthcare system and proposed adjunctive statements aimed at favouring its suitability.

The results obtained by the breakout groups were then reported to the whole taskforce, who discussed the proposed statements, amended them and arrived at final wordings that were subject to an open voting process through a show of hands. Items that achieved at least a 80% majority vote were accepted as final statements in the same way as they had been worded. This process led to formulate 27 statements, which, together with the 12 EULAR/PreS recommendations, were included in a final 39-item survey.

The survey was, then, submitted online to all 27 members of taskforce, who were asked to vote the applicability of the EULAR/PreS recommendations

and their agreement with the newly proposed country-specific statements on a 0–10 scale (1 = no applicability or agreement at all; 10 = full applicability or agreement). The minimum level of agreement among respondents for item acceptance was 80% (*i.e.* mean agreement ≥ 8) (14).

During the final consensus meeting, which was held in Rome on December 21, 2017, all statements that had not achieved consensus after the first round of voting were re-discussed, reformulated and re-voted using the same 0–10 scale. The statements that did not achieve a mean agreement ≥ 8 among taskforce members were discarded. Then, a final document was written that included all statements that had reached consensus.

Results

Results of voting on applicability of EULAR/PreS recommendations and agreement on country-specific statements

The 39 items included in the online survey are listed in Table I, together with the mean level of applicability of the EULAR/PreS recommendations to the Italian rheumatology practice and health care system and the mean agreement of the taskforce with the newly proposed country-specific statements. The overall response rate was 100% for all items in both voting rounds. Table II presents the comparisons of voting made by paediatric and adult rheumatologists.

The mean consensus threshold of 8 for the applicability to the Italian rheumatology practice and health care system was reached by only 4 of the 12 EULAR/PreS recommendations. Of the 27 newly proposed country-specific statements, 22 achieved a mean level of agreement ≥ 8 in the first voting round. The 5 statements without consensus (2A, 2D, 4C, 6A and 7A) were re-discussed in the final consensus meeting and, with the exception of statement 2A, reworded. All 5 statements were, then, re-voted. Statements 2D, 6A and 7A reached consensus and were, thus, included in the final document, whereas statements 2A and 4C did not achieve consensus and were discarded.

The final reworded version of statements 2D, 4C, 6A and 7A is reported in Table I.

Evaluation of EULAR/PreS recommendations and formulation of country-specific statements

Herein we report a summary of the discussions that took place among the members of the taskforce regarding the suitability of the EULAR/PreS recommendations to the Italian environment and emphasise for each of them the main comments or concerns that were raised by the taskforce members. In addition, we analyse the rationale that underlies the proposal of the new statements aimed to foster the applicability of the EULAR/PreS recommendations in Italy.

Recommendation 1:

YP with RMD should have access to high-quality, co-ordinated transitional care, delivered through partnership with healthcare professionals, YP and their families, to address needs on an individual basis

This recommendation did not achieve consensus about its applicability (mean level of 7.04) and was, together with recommendation 2, the most debated. The low level of applicability attributed to this recommendation depended on the skepticism among paediatric and adult physicians about reciprocal collaboration, the current lack of a formal definition and organisation of the transition process in Italy and the paucity of care facilities with both paediatric and adult rheumatology teams available (statement 1A). It was considered mandatory before implementing a TC network in the country to map all centres which already have an active TC clinic or are willing to establish one (statement 1B). It was also recognised that the different management attitudes of paediatric and adult rheumatologists may hamper an effective coordination. Solving this problem requires training initiatives focused on the specific characteristics and needs of YP with rheumatic diseases and enhanced collaboration and sharing of clinical information between paediatric and adult rheumatologists (statements 1C and 1D).

Table I. Final consensus on the applicability of EULAR/PreS recommendations for the transitional care of young people with juvenile-onset rheumatic diseases and level of agreement with country-specific statements.

EULAR/PreS recommendations and country-specific statements issued by the Italian taskforce		Mean level of applicability (0-10)	Mean agreement (0-10)
1.	<i>YP with RMD should have access to high-quality, co-ordinated transitional care, delivered through partnership with healthcare professionals, YP and their families, to address needs on an individual basis</i>	7.04	
1A)	The lack of coordination and the poor collaboration between paediatric and adult rheumatologists may depend on the paucity of structures endowed with both specialists		8.89
1B)	To foster the TC network, it is necessary to map all centres that possess a TC clinic or are willing to implement one		9.11
1C)	The paucity of dedicated centres and the difficulty to identify the needs of each individual patient undergoing TC require a training program focused on the issues related to adolescents and young adults		8.96
1D)	The harmonisation of the approach to disease management between paediatric and adult rheumatologists requires greater collaboration and sharing of clinical information, even electronically		8.78
2.	<i>The transition process should start as early as possible in early adolescence or directly after the diagnosis in adolescent-onset disease</i>	6.04	
2A)	The time of start of transition may depend on the state of disease activity		Not validated
2B)	The care of juvenile-onset rheumatic diseases pertains to the paediatrician		8.22
2C)	The transitional process must begin after the achievement of a good disease control between the age of 14 and 16 years (not earlier than 14 years). The decision about the optimal time of transition start should be made on a case-by-case basis and is up to the paediatric rheumatologist		8.41
2D)	In case the disease onset occurs after the age of 14 years, it is appropriate to activate as soon as possible the transition to adult rheumatology care		8.00
3.	<i>There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer, there should be 'direct' contacts between paediatric and adult rheumatologist teams</i>	7.70	
3A)	There is a paucity of centres which possess both paediatric and adult rheumatologists		8.59
3B)	A regional mapping of adult rheumatology centres may help the paediatric rheumatologist to identify the adult specialist to whom the YP may be referred, in agreement with YP and their family		8.63
3C)	It is necessary to identify regional TC reference centres that may organise training courses		8.67
4.	<i>Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families</i>	8.41	
4A)	Due to the heterogeneity in collecting data and information to be shared at the time of transition, to make the transitional care documentation consistent and complete it is necessary to create a standardised format, which include a minimum dataset		8.96
4B)	The timeline for the transition process should be planned together with the patient family and should be based on clinical, epidemiological and logistic factors		8.93
4C)	The availability of tools for self-assessment of disease and health status, even online, may constitute an effective mean to support transitional care		Not validated despite rewording
5.	<i>Every rheumatology service and clinical network—paediatric and adult—must have a written, agreed and regularly updated transition policy</i>	7.67	
5A)	The TC process should be guided by written and regularly updated recommendations, which must be approved not only locally but also at the national level (i.e. by the healthcare system and scientific societies)		8.56
6.	<i>There should be clear written description of the MDT involved in transitional care, locally and in the clinical network. The MDT should include a designated transition co-ordinator</i>	7.48	
6A)	The MDT must include a designated transition co-ordinator, specifically trained to manage the complex issues of childhood-onset rheumatic diseases		9.08
7.	<i>Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development</i>	8.41	
7A)	It is important to train adult rheumatologists on the communication with paediatric patients		9.50
7B)	During the course of transition, it is important to switch progressively the attention of the caring physician from the parent to the child, even through dedicated questionnaires		8.37
7C)	It is crucial to encourage the YP to become responsible for the management of their own illness in order to favour adherence to therapeutic prescriptions		9.00
8.	<i>There must be a transfer document</i>	8.89	
8A)	The transfer document must include a well-defined core-set of information		9.19
8B)	The transfer document is important to establish a common language, even in terms of clinimetric assessments, between paediatric and adult rheumatologists		9.48
9.	<i>Healthcare teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent care and childhood-onset RMD</i>	8.11	
9A)	The current lack of training and administrative support to TC may be improved by involving hospital managements and administrations and scientific societies	8.48	
10.	<i>There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care</i>	7.63	
10A)	A national initiative may enhance the awareness of the importance of transition from paediatric to adult rheumatology teams		8.04
11.	<i>There must be a freely accessible electronic-based platform to host the recommendations, standards and resources for transitional care</i>	8.33	
11A)	The TC information should also be disseminated by scientific societies		8.96
12.	<i>Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood-onset RMD</i>	8.52	
12A)	The clinimetric measures for adults with childhood-onset rheumatic diseases are currently not defined. This limitation hampers a correct disease monitoring and outcome assessment		8.04
12B)	It is of paramount importance to develop and validate appropriate clinimetric assessments		8.37
12C)	For adults with childhood-onset rheumatic diseases, there is the need for a greater number of therapeutic trials and pharmaco-economic studies		8.00

YP: young people; RMD: rheumatic musculoskeletal disease; NHS: National healthcare system; MDT: multidisciplinary team.

Table II. Comparison between voting of paediatric and adult rheumatologists.

Item	Level of applicability		Level of agreement	
	Paediatric	Adult	Paediatric	Adult
R 1	6.50 (3-10)	7.62 (3-10)		
S 1A			8.57 (6-10)	9.23 (8-10)
S 1B			8.86 (7-10)	9.38 (8-10)
S 1C			9.29 (7-10)	8.62 (6-10)
S 1D			8.71 (5-10)	8.85 (7-10)
R 2	5.07 (1-10)	7.08 (2-10)		
S 2A			8.79 (4-10)	7.08 (0-9)
S 2B			9.29 (7-10)	7.08 (4-10)
S 2C			8.07 (5-10)	8.77 (5-10)
S 2D			5.14 (0-9)	8.54 (6-10)
R 3	7.71 (6-10)	7.69 (4-10)		
S 3A			8.14 (5-10)	9.08 (8-10)
S 3B			8.29 (4-10)	9.00 (7-10)
S 3C			8.93 (6-10)	8.38 (5-10)
R 4	8.64 (6-10)	8.15 (5-10)		
S 4A			8.93 (7-10)	9.00 (6-10)
S 4B			9.14 (7-10)	8.69 (7-10)
S 4C			7.64 (5-10)	7.62 (4-10)
R 5	7.79 (4-10)	7.54 (4-10)		
S 5A			8.36 (4-10)	8.77 (6-10)
R 6	7.29 (3-10)	7.69 (5-10)		
S 6A			4.50 (0-10)	8.54 (5-10)
R 7	8.50 (4-10)	8.31 (5-10)		
S 7A			7.21 (0-10)	7.85 (5-10)
S 7B			8.36 (0-10)	8.38 (6-10)
S 7C			9.29 (7-10)	8.69 (5-10)
R 8	9.00 (7-10)	8.77 (7-10)		
S 8A			9.14 (7-10)	9.23 (8-10)
S 8B			9.50 (8-10)	9.46 (8-10)
R 9	8.00 (2-10)	8.23 (5-10)		
S 9A			8.21 (4-10)	8.77 (7-10)
R 10	7.50 (2-10)	7.77 (3-10)		
S 10A			8.14 (5-10)	7.92 (2-10)
R 11	8.21 (5-10)	8.46 (6-10)		
S 11A			9.07 (6-10)	8.85 (7-10)
R 12	8.29 (5-10)	8.77 (6-10)		
S 12A			7.79 (2-10)	8.31 (5-10)
S 12B			8.07 (1-10)	8.69 (6-10)
S 12C			7.57 (2-10)	8.46 (6-10)

Data are the mean (range). R: EULAR/PRoS recommendation; S: country-specific statement.

See Table I for definitions of EULAR/PRoS recommendations and country-specific statements.

Recommendation 2:

The transition process should start as early as possible in early adolescence or directly after the diagnosis in adolescent-onset disease

Its level of applicability (6.04) was the lowest of the 12 EULAR/PRoS recommendations. Consensus was lower among paediatric rheumatologists than among adult practitioners (5.07 vs. 7.08). This discordance reflects the controversies related to the optimal time to begin the transition process. The prevailing opinion among paedia-

tricians was that the age of start differs between patients and does not depend only on the disease state, but also on the developmental and maturation stage of the individual patient. There was controversy also about the statements issued to adapt this recommendation to the Italian environment. Statement 2A, which indicated that the time to start transition depends on the state of disease activity, did not reach consensus among the whole task force even after the second vote and was discarded. The state of disease activity was deemed as

important, but not sufficient, to establish the start of the transition process. Paediatric and adult rheumatologists agreed that in case the patient has active disease no transition should occur. Such patient should be assessed jointly by paediatric and specialists for at least 2-3 visits and transition should be initiated when the disease is stable.

Although approved by the whole task force, statement 2B, which said that the juvenile-onset disease pertains to the paediatrician, achieved consensus among paediatricians, but not among adult specialists. It was, however, agreed upon that at the very beginning transition does not require either the presence of the adult rheumatologist or a joint clinic. Rather, the first step of the process should involve the transmission of the information related to the TC by paediatric rheumatologists to patients and their families. Like statement 2B, statement 2D, mandating the evaluation of the transition toward adult care as soon as possible in case the disease has its onset after the age of 14, was approved by the entire task force, but was agreed upon by one sole group of specialists (in this case adult rheumatologists).

The only statement pertaining to this recommendation that was approved by both paediatric and adult specialists was the 2C, which says that transition must begin after the achievement of good disease control, not earlier than the age of 14. The decision when to start the transition process is left to the paediatric practitioner and should be made on a case-by-case basis.

Recommendation 3:

There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer, there should be 'direct' contacts between paediatric and adult rheumatologist teams

Although the mean level of applicability of this recommendation did not reach the minimum threshold of 8, there was wide agreement among the task force members that the choice of the adult rheumatologists to whom to refer the

patient should be left to the paediatric specialist. The reasons for the incomplete applicability of this recommendation are reflected in the additional statements, which emphasised the paucity of centres with the onsite availability of both paediatric and adult rheumatologists, the need of mapping the adult rheumatology centres in the country that are available to make TC and the usefulness of organising training courses in TC at the regional level (statements 3A, 3B and 3C).

Recommendation 4:

Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families

There was wide consensus about the applicability of this recommendation and the adjunct statements highlighted the utility of creating a uniform dataset to ensure consistency and completeness of the documentation and the foremost importance of planning the transition process with the patient and the family (statements 4A and 4B). Regarding the latter statement, the task force members acknowledged that planning the individual transition process with the parents can be challenging due to their reluctance to accept a reduced presence at clinic visits.

Statement 4C, which underscored the potential utility to support TC of paper or online tools for self-assessment of disease and health status was not approved, even after rewording. Some participants said that electronic records that may ease sharing of the information already exist in some regions. Others highlighted the potential role of the new technologies, particularly smartphones and touch-screen devices, in helping YP to become responsible for their own health and life and in improving self-advocacy and self-management skills. However, no agreement could be reached on this statement.

Recommendation 5:

Every rheumatology service and clinical network – paediatric and adult – must have a written, agreed and regularly updated transition policy

The lack of approval of this recommen-

dation is explained by the recognition of the difficulty to have all centres involved in TC to develop a written and agreed transition policy and to update it regularly. However, the addition of the requirement that the written and updated TC document must be approved not only locally, but also by the national health care system and scientific societies (statement 5A) obtained a wide agreement.

Recommendation 6:

There should be clear written description of the MDT involved in transitional care, locally and in the clinical network. The MDT should include a designated transition co-ordinator

The task force did not deem sufficiently applicable this recommendation, but agreed with the associated requirement that the multidisciplinary team must designate a transition coordinator, who should be trained in the management of paediatric rheumatic diseases (statement 6A). The first version of this statement, which indicated the adult rheumatologist as the transition coordinator reached the lowest level of agreement across specialists (4.05 and 8.54 among paediatric and adult rheumatologists, respectively). The reworded version of the statement, which did not mention the characteristics of the transition coordinator, was approved smoothly.

Recommendation 7:

Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development

Both paediatric and adult rheumatologists agreed that units devoted to TC should be focused to YP and be able to address appropriately and thoroughly their developmental needs. It was, however, recognised that dealing with YP is more difficult for adult rheumatologists due to their limited experience with adolescents. An additional statement (statement 7A) was then added, which mandates the training of adult practitioners in the communication skills with paediatric patients. This objective should be pursued through dedicated courses, which should include the preparation to address the

physical, psychological, educational and vocational development of adolescents. Participants agreed that the paediatrician may help the adult rheumatologist to learn how to communicate with young people.

It was also underscored (statement 7B) that the attention of the caring physician during the process of transition must be progressively switched from the parent to the patient to stimulate self-advocacy, independence and self-management. Promoting self-care was deemed important to favour adherence to prescribed therapeutic regimens (statement 7C).

Recommendation 8:

There must be a transfer document

This recommendation, which reached the highest mean level of agreement, was integrated with the need that the transfer document incorporates a defined, preferably standardised, core-set of information (statement 8A). There was an intense discussion about the opportunity to harmonise the clinimetric assessments across paediatric and adult rheumatologists, as it would help to establish a common language among specialists and to follow more reliably the disease course over time after the transfer of the patient to the adult care (statement 8B). It was decided that one of the main topics of future collaborations between the Italian paediatric and adult rheumatology scientific societies should be the organisation of consensus efforts aimed at creating uniform clinimetric measurements for childhood-onset rheumatic diseases across all ages.

Recommendation 9:

Healthcare teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent care and childhood-onset RMD

Although this recommendation was agreed upon, concern was raised that the lack of training and the shortage of resources may hamper its applicability. The support of the national health care system, hospital administrations and scientific societies was deemed critical to promote training of health professionals in generic adolescent care and

in the specific aspects of childhood-onset rheumatic diseases (statement 9A).

Recommendation 10:

There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care

Continuity of care is a key feature of TC (17). However, this recommendation was not approved because nowadays no funding dedicated to TC is available in Italy. To get financial support, participants hoped the launch of a fund-raising campaigns at the national level (statement 10A).

Recommendation 11:

There must be a freely accessible electronic-based platform to host the recommendations, standards and resources for transitional care

Participants shared this suggestion of the EULAR/PReS taskforce, as a freely accessible electronic-based platform that hosts the protocols and resources would greatly facilitate the conduction and standardisation of TC in different centres. The active engagement of scientific societies was considered important to apply this recommendation (statement 11A).

Recommendation 12:

Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood-onset RMD

The taskforce agreed that the enhancement of evidence-based knowledge and practice may improve the long-term outcomes of patients with childhood-onset rheumatic diseases. The development and validation of homogeneous clinimetric measurements across paediatric and adult practice and the conduction of more efficacy and pharmacoeconomic studies were deemed to be crucial steps to accrue this knowledge (statements 12A, 12B and 12C). However, although all added statements obtained the approval, they were overall more agreed upon by adult rheumatologists than by paediatric specialists.

Discussion

We have reported the results of a Delphi expert consensus survey regarding the

implementation of TC for YP with JIA in Italy. Despite the widely advocated establishment of a standardised model of TC for YP with JIA, there was concern that the conduction of TC in Italy was largely heterogeneous and that the respective role of paediatric and adult rheumatologists was not clarified.

At the beginning of the process, it was decided that the starting point should be the analysis of the EULAR/PReS recommendations, which provide a framework and specific standards that are aimed to guide the development of high-quality transition programs in individual countries. However, when the applicability of the 12 recommendations to the Italian rheumatology practice and health care system was discussed and voted, only 4 of them reached the minimum agreement threshold among taskforce members. The main reasons that explained the poor agreement were the paucity of centres in Italy that possess both paediatric and adult rheumatologists; the disagreement between paediatric and adult practitioners about the optimal age/time and disease stage at which to begin transition; the uncertainty about the health care professional who should act as transition coordinator; the diversity of clinimetric assessments used by paediatric and adult rheumatologists; the lack of support by public healthcare authorities, hospital administrations, and scientific societies; and the scarcity of funding devoted to TC.

To overcome the limitations in the applicability of the EULAR/PReS recommendations and enhance their suitability to the Italian environment, additional consensus statements were proposed for each recommendation. The statements emphasised several practical issues that must be addressed in the upcoming future. Of them, the most relevant are the identification and involvement of adult rheumatology centres throughout the country that are available to take part in the TC process; the improvement of skills and knowledge of adult rheumatology teams on the characteristics and treatment of childhood-onset rheumatic diseases and the general transition issues; the definition of a uniform and standardised transfer document; the en-

agement of public health authorities, hospital administrations, scientific societies and parent/patient organisations; and the search for dedicated financial support.

Overall, all taskforce members considered that the EULAR/PReS recommendations in their original formulation are appropriate to guide the TC of YP with JIA and can, therefore, be adopted in their entirety in Italy. However, it was felt that to facilitate their effective application there was the need to address local implementation issues. Thus, according to a recently proposed categorisation (18), the consensus effort described in this manuscript should be regarded as a contextualisation process, rather than an adoption or adaptation of existing guidelines.

In conclusion, the effort described herein represents an important step forward toward the establishment of a nationwide TC network for YP with JIA in Italy. Although much work is yet to be done, it is hoped that the strong commitment of both paediatric and adult rheumatology communities will lead to create well-established TC services, to increase the awareness of the importance of good-quality TC among public healthcare authorities and other stakeholders involved in the care of YP with childhood-onset rheumatic diseases and to overcome the scarcity of financial resources.

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