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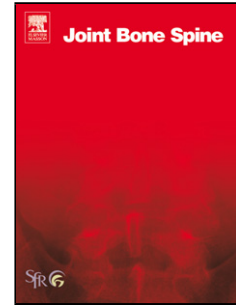
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**Building a transitional care checklist in rheumatology: a Delphi-like survey**

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**Abstract**

**Objectives.** To design a transitional care checklist to be used by and facilitate the work of health professionals in providing transitional care for children with a chronic rheumatologic disease and their families.

**Methods.** A Delphi-like study among an international expert panel was carried out in four steps: 1)a working group of 6 specialists established a draft; 2)a web-survey among a panel of international experts evaluated it; 3)a 2-day consensus conference with an expert panel discussed items not reaching agreement; 4)a web-survey among the panel of international experts with the list of reformulated items.

**Results.** The first draft of the checklist included 38 items in 3 phases of transition and 5 age groups. Thirty-three international experts evaluated the checklist reaching  $\geq 80\%$  agreement for 26 items and  $\leq 80\%$  for 12. The consensus conference of 12 experts discussed and redefined the 12 items. Twenty-five international experts filled out the web-survey and all items reached a minimum of 80% agreement except one. The final checklist was reached.

**Conclusions.** This Delphi-like study defined what themes should be included and at what age they need to be addressed with patients with a chronic rheumatology disease and their families during transition. This checklist reached a strong international and interdisciplinary consensus while examining transition in a broad way. It should now be spread widely to health professionals to be used by all those who care for adolescents aged  $\geq 12$  years at times of transition. It could be transposed to most chronic conditions. Recommendations for further research are given.

**Keywords**

Transition; Checklist; Delphi study; Chronic condition; Adolescent

## 1. Introduction

Transitional care for adolescents with a chronic condition is a growing field of research. It has notably put forward that continuity of care during adolescence increases the chances for patients to remain integrated in the healthcare system while decreasing risks for long-term poor health outcomes (1). However, studies have also shown that very low percentages of youths with chronic conditions receive any transition information or preparation from health professionals (2-4). A Swiss study reported that only half of 14-25 year olds had discussed their transfer to adult care (5).

Despite the need to improve transitional care for these adolescents, health professionals often lack an established protocol and programs are most often limited to a simple transfer (6). This lets forth more specific or local initiatives than systematic transition programs. Nonetheless, evidence exists that transition programs do make a difference. For example, rates of successful transition have shown to increase when transition programs are in place (7); young adults feel better accompanied when they have discussed transition with their pediatric specialist (8); and young people having gone through transition programs have a higher satisfaction, perceived health status, and emotional and physical quality of life (9, 10).

In line with this, recommendations have been published regarding what needs to be part of a transition program in general (11-13). A few transition checklists for health professionals have been built around the world; for examples see references (14-16). However, to our knowledge, no checklist has ever been put together in Switzerland or in France. Moreover, transition can be a long process that needs to start early on in age in pediatric care and finish many years later once established in adult care; thus there is a need to define what steps entail to be done at what point in time. Different stakeholders also need to be included in transitional care: the medical team/health professionals, the adolescent him/herself, and his/her parents/caregivers. As a result, a structured and concrete checklist is required in order to know how, what, and when the different stakeholders need to do during the transition process.

The aim of this study was to design a transitional care checklist that can be used by and facilitate the work of health professionals in providing transitional care for children with a chronic rheumatologic disease and their families/parents.

## 2. Methods

To build a transitional care checklist for health professionals, a Delphi-like study among an international expert panel was carried out in four steps (*Figure 1*). During the first step, a working group of 6 specialists (2 pediatric rheumatology doctors, 1 adult rheumatology doctor, 1 transition nurse in rheumatology, 1 family doctor specialized in adolescent health care, 1 pediatrician specialized in adolescent health care) met several times to establish a first draft of a transitional care checklist. They met 5 times until finding a consensus on a first draft of the checklist that included 38 items.

For the second step, the draft checklist was sent as a web-survey to a panel of international experts in rheumatology to evaluate it. Experts were asked to assess each of the 38 items of the checklist

according to 7 possible answers: (1) "Agree, leave it as it is"; (2) "Agree, but needs to be reformulated"; (3) "Agree, but should be moved to another phase"; (4) "Agree, but should be moved to another age"; (5) "Partially disagree"; (6) "Completely disagree, should be removed"; (7) "Other". Participants could also chose to enter a comment for each possible answer except for the first one ("Agree, leave it as is").

The third step consisted in organizing a 2-day consensus conference with an expert panel present to discuss the items that did not reach an agreement in the web-survey. Items that scored less than 70% agreement during the first survey were discussed, reformulated and re-voted on. The items that scored between 70% and 80% during the first survey were discussed briefly to see if they could be improved. Those that had reached an 80% agreement or above were not re-discussed.

In the fourth and last step, the list of items that had scored less than 80% during the first survey and reformulated during the consensus meeting was resubmitted as a web-survey to the panel of international experts in rheumatology (the same as for the first survey) with the same 7 possible answers for each item and possibility to leave a comment.

### 3. Results

During the first step, the working group of 6 experts in transition built a first draft of the checklist that included 38 items spread out into 3 phases of transition and 5 age groups indicating when event should take place: (1) A *Preparation phase* divided into 2 age groups: 12-14 y.o. and 14-16 y.o.; (2) A *Transfer phase* divided into 2 age groups: 16-18 y.o. and 17-22 y.o.; (3) An *Engagement phase* going from 20-24 y.o. (*Table*)

During the second step consisting of the first web-survey, 47 international experts in rheumatology or transition were contacted based on the French national network on rare autoimmune and autoinflammatory diseases (FAI2R) and personal networks. All 47 agreed to participate, and 33 actually answered (70.2% response rate; 2 were unable to respond, 12 did not respond despite 3 reminders). Experts were 14 pediatricians, 10 rheumatologists, 5 immunologists, 2 nurses, 1 adolescent doctor, and 1 patient. In 26 items, we reached  $\geq 80\%$  agreement; in 5 items,  $\geq 70\%$ ; in 6  $\geq 60\%$ ; and in 1  $\geq 50\%$ . (*Table 1*).

The third step, the consensus conference of experts gathered during 2 days 12 health professionals (6 pediatric rheumatology, 4 adult rheumatology and 2 adolescent health specialists, among them 1 nurse and 1 physical therapist). During the conference, the 12 items that had reached less than an 80% consensus during the web-survey (5 dubious: 70-79.9% and 7 disagreed  $< 70\%$ ) were discussed. The 12 items were first discussed in small groups to propose wording changes, and then in a plenary session and each item was voted on. In the end 11 items were reformulated and 1 stayed unchanged (item 3.3) (*Table*). Even though they were not supposed to be re-discussed, some participants suggested slight rewording for better comprehension for 3 out of the 26 items that had reached  $\geq 80\%$  agreement.

In the fourth step, the second survey, the 33 international experts in rheumatology who had answered the first web-survey were sent the list of 12 items that had reached less than an 80% consensus during the first vote to participate again. Out of the 33, 27 agreed to answer (81.8% response rate) and 25 filled

out the questionnaire (2 left it blank). The 3 items that had been reworded slightly for better comprehension were not re-voted on as they had already reached a  $\geq 80\%$  agreement. At this point, all items reached a minimum of 80% agreement except for 1 item (item 4.2) that reached a 72% agreement. For the latter, 24% agreed on the item but thought it should be moved to another age – which should be later according to comments – and 4% agreed with the item but thought it should be reformulated (data not shown). However, no one wished to have it removed. Likewise, no item was removed at any point. At the end of the fourth step, the final checklist was reached.

#### 4. Discussion

This Delphi-like study was a four-step process to build a transitional care checklist with the help of an international panel of experts in the field. Given the overall high percentages of agreement, this checklist appears to reach a high consensus among experts. As a result, it defined what themes should be included and at what age they need to be addressed with patients with a chronic rheumatology disease and their families during transition.

Concerning age, there was not much discussion at any step of the process on when different subjects need to be brought up with patients and there was an overall high agreement in this regard. The only exception concerned item 4.2 which stayed similar to the first round going from 75.8% to 72% agreement. Indeed, this lower percentage seemed to come mainly from a lack of consensus regarding at what age the vocational issues need to be discussed. We know that future professional life of adolescents with chronic conditions is a delicate subject that parents often forget to consider early on (17) or that do not consider at all as overprotection is a common reaction among these parents (18, 19). It is also known that these youths are often not pushed to their full potential and they are less likely to reach the same professional milestones than their peers (20). Given the difficulty of handling this issue in families, there could also be a worry among health professional about raising the issue too early. This is surprising in countries like Switzerland or France where 16 years is often too late to start thinking about future professional life: mandatory school goes up to age 15, after which about one third of adolescents follow high-school and two-thirds vocational education. The latter need to find an apprenticeship where they are enrolled by companies to train for their future profession and attend class at vocational schools only 1-2 days a week. Hence, given the national context and knowing that youths with chronic conditions have lower odds of graduating from high school (20) or college (21) and being employed (20-22), and higher odds of having a lower income (21) and receiving public assistance (20, 21), health professionals need to address the professional matter early on.

The 12 items that brought up the most disagreement and discussion and that were re-voted on in the second web survey seemed to have in common to be too vague. Indeed, 11 of them were reworded to be more precise regarding their meaning. We can thus conclude that efforts were made among the professionals present at the consensus conference to define a checklist that is as concrete, usable, and understandable by all professionals, avoiding as much as possible items that might be unclear or confusing in daily clinical practice. The second vote setting all percentages above 80% confirmed its success.

Consensus-based recommendations for transitional care that exist, whether for young people with chronic conditions in general (11) or with juvenile-onset rheumatic diseases specifically (12) reinforce our findings in three major ways. First, in terms of the importance of the coordination between pediatric and adult professionals and of using transition policies and tools were the reasons for establishing such a checklist. Second, starting in early adolescence corresponds to the reason why the checklist starts at age 12. Third, communication between pediatric and adult health professionals which corresponds to items 15 to 25 on our checklist. The commonalities between these studies and our findings put forth a strong need for concrete tools that could be used on a daily clinical base such as this checklist to ameliorate transitional care.

This checklist reaches a strong international and interdisciplinary consensus and examines transition in a broad way. It should now be spread widely to health professionals in order to be used as much as possible by all those who care for adolescents at times of transition starting at age 12. Although it was thought out to be used in rheumatology, it seems possible to be transposed to most chronic conditions. There are no disease specific aspects in this checklist and it can ameliorate the care of 12-24 year old patients with chronic conditions and their families.

Further research should thus go two ways. First, future studies must validate the checklist considering feasibility in a non-categorical approach to chronic conditions in daily clinical practice. This ought to be done with health professionals coming from different medical specialties (for example endocrinologists, pulmonologists, gastroenterologists, etc.) of pediatric and adult medicine. Moreover, the checklist needs to be evaluated by adolescents and parents to make sure nothing was forgotten. Second, further research needs to assess the effectiveness of the checklist on young adults' health and transition outcomes. This can confirm the importance of a structured transition policy by using such a transition checklist in order to improve many current problems present after patient transfer to adult medical care such as poor clinical outcomes (23), lost at follow-up rates, hospitalization admissions (24), decline in health status (25), emotional and physical quality of life (9, 10), and education and employment (21).

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Accepted Manuscript

Table 1: Transitional care checklist process to final agreement

AGE*	ITEMS AT BASELINE (T0)	1 <sup>ST</sup> SURVEY AGREEMENT	ITEMS AFTER CONSENSUS MEETING (T1)	2 <sup>ND</sup> SURVEY AGREEMENT
	<b>PREPARATION PHASE</b>			
12-14	1. First discussion on transition		1. First discussion on transition	
	1.1 Discussing the concept of transition and its importance	<b>81.8%</b>	1.1 Discussing the concept of transition and its importance with patient and parents	<b>Not discussed (ND)</b>
	2. A transition plan is established with milestones		2. A transition plan is established with milestones	
	2.1 Agreeing with patient and parents on a calendar with clear (but flexible) milestones	<b>75.8%</b>	2.1 Agreeing with patient and parents about the transition process and specific (although flexible and individually adapted) steps to reach autonomy and transit to adult care.	<b>84%</b>
	3. The physician starts to see the patient without his parents		3. The physician starts to see the patient without his parents	
	3.1 Patient and parents are (nicely!) informed that the physician will see the patient alone (at least partially) from the next consultation on. Reasoned explanations for it are given.	63.6%	3.1 Patient and parents are given reasoned explanations for the adolescent to be seen alone for at least part of the consultation.	<b>96%</b>
	3.2 Patient is seen (at least partially) alone.	66.7%	3.2 Patient is seen without parents during part of the consultation, mainly to discuss the HEEDSSS questionnaire and feelings regarding the disease, treatment and pain	<b>84%</b>
	3.3 Physician discusses with parents their new role as transition plan advances	<b>75.8%</b>	3.3 Physician discusses with parents their new role as transition plan advances	<b>90%</b>
	4. Define the expectations (educational/professional) of patient and parents		4. Define the expectations (educational/professional) of patient and parents	
	4.1 Define the educational expectations of the patient	<b>84.8%</b>	4.1 Define the educational expectations of the patient	<b>ND</b>
4.2 Define the professional expectations of the patient	<b>75.8%</b>	4.2 Start discussing vocational options with the patient	72%	
14-16	5. Discussion on the effect of legal substances on the disease and treatment		5. Discussion on the effect of legal substances on the disease and treatment	
	5.1 Discussion on the effect of smoking on the disease and its treatment	<b>84.8%</b>	5.1 Discussion on the effect of smoking on the disease and its treatment	<b>ND</b>

5.2 Discussion on the effect of alcohol use and misuse on the disease and its treatment	<b>87.9%</b>	5.2 Discussion on the effect of alcohol use and misuse on the disease and its treatment	<b>ND</b>
6. Discussion on the effect of illegal substances on the disease and treatment		6. Discussion on the effect of illegal substances on the disease and treatment	
6.1 Discussion on the effect of cannabis use on the disease and its treatment	<b>90.9%</b>	6.1 Discussion on the effect of cannabis use on the disease and its treatment	<b>ND</b>
6.2 Discussion on the effect of the use of other illegal drugs on the disease and its treatment	<b>84.8%</b>	6.2 Discussion on the effect of the use of other illegal drugs on the disease and its treatment	<b>ND</b>
7. Discussion about the effects of the condition on Sexuality/Fertility/Pregnancy and effect of treatment(s) on fertility		7. Discussion about the effects of the condition on Sexuality/Fertility/Pregnancy and effect of treatment(s) on fertility	
7.1 Discussion about the effects of the condition on Sexuality/ Fertility/Pregnancy	<b>75.8%</b>	7.1 Health professional provides information to patient and parents about the effects of the condition and the treatment on sexuality, fertility, and pregnancy	<b>92%</b>
7.2 Discussion about the effects of treatment(s) on fertility	69.7%	7.2 Discussion with patient, but without parents, on the personal aspects/behaviors of the information regarding sexuality, fertility, and pregnancy. Ideally in a second consultation	<b>88%</b>
8. The patient knows how to react in case of emergency		8. The patient knows how to react in case of emergency	
8.1 The signs and symptoms to rush to the ER are explained to the patient so that s/he knows how to react	<b>87.9%</b>	8.1 The signs and symptoms to rush to the ER are explained to the patient so that s/he knows how to react	<b>ND</b>
8.2 The signs and symptoms to consult (but not to the ER) are explained to the patient so that s/he knows how to react	<b>84.8%</b>	8.2 The signs and symptoms to consult (but not to the ER) are explained to the patient so that s/he knows how to react	<b>ND</b>
9. The differences between pediatric and adult care are explained		9. The differences between pediatric and adult care are explained	
9.1 Explain the different approaches noted globally between pediatric and adult care	<b>81.8%</b>	9.1 Explain the different approaches noted globally between pediatric and adult care	<b>ND</b>
9.2 If this is the case, explain the different approaches noted between pediatric and adult care the patient will be referred to.	<b>81.8%</b>	9.2 If this is the case, explain the different approaches noted between pediatric and adult care the patient will be referred to.	<b>ND</b>
10. The patient is able to describe his disease		10. The patient is able to describe his disease	
10.1 Patient can accurately describe her/his disease in a few sentences	<b>87.9%</b>	10.1 Patient can accurately describe her/his disease in a few sentences	<b>ND</b>

	11. The patient is able to describe his treatment		11. The patient is able to describe his treatment	
	11.1 Patient can describe her/his medication and what they are used for	<b>90.9%</b>	11.1 Patient can describe her/his medication and what they are used for	<b>ND</b>
	12. The patient is able to book his/her own consultations		12. The patient is able to book his/her own consultations	
	12.1 Patient knows the process of booking a consultation	69.7%	12.1 Empower the patient to be able to contact the Transition Manager in case of need	<b>84%</b>
	13. All previous steps were completed		13.All previous steps were completed	
	13.1 Physician makes sure that all elements above are acquired (or makes a list of those that need to be acquired later on to inform the adult physician)	<b>93.9%</b>	13.1 Physician makes sure that all elements above are acquired (or makes a list of those that need to be acquired later on to inform the adult physician)	<b>ND</b>
	14. <i>Transfer readiness test</i>		14.Transfer readiness test	
	14.1 <i>A transition readiness test (to be chosen) is given to patient and parents to be sure of their readiness to be transferred.</i>	69.7%	14.1 A standardized transition readiness assessment is given to patient and parents to evaluate their readiness to be transferred	<b>80%</b>
17-20	<b>TRANSFER PHASE</b>			
	15. Identification of adult care representative		15. Identification of adult care representative	
	15.1 Pediatric provider identifies an adult provider according to the preferences/characteristics of the patient (and family)	<b>87.9%</b>	15.1 Pediatric provider identifies an adult provider according to the preferences/characteristics of the patient (and family)	<b>ND</b>
	16. Set-up the transfer protocol		16. Set-up the transfer protocol	
	16.1 A transfer protocol between pediatric and adult providers is set up (or adapted to the needs if protocol already exists)	<b>90.9%</b>	16.1 A transfer protocol between pediatric and adult providers is set up (or adapted to the needs if protocol already exists)	<b>ND</b>
16-18	17. First contact with the adult team		17. First contact with the adult team	
	17.1 A first contact (could be by phone and could not be needed if #17.2 is possible) is made with the adult team	<b>87.9%</b>	17.1 A first contact (could be by phone and could not be needed if a common consultation is possible) is made with the adult team	<b>ND</b>
	17.2 If possible, at least one common pediatric/adult consultation is done	<b>81.8%</b>	17.2 If possible, at least one common pediatric/adult consultation is done	<b>ND</b>
17-22	18. First consultation in adult care		18. First consultation in adult care	
	18.1 A first consultation alone in adult care is made	<b>75.8%</b>	18.1 A first consultation with the adult team is made (other than a common one with pediatrics)	<b>88%</b>
	19. Feed-back on the first consultation		19. Feed-back on the first consultation	

	19.1 Feedback on the first consultation from patient AND parents is given to the pediatric team to assure that everything went well and as expected	66.7%	19.1 Standardized feedback (could be online) of the first consultation in adult care (NOT a common consultation) from the patient (and parents if needed/wanted) should be given to the transition manager	<b>84%</b>
	20. Second / final consultation in adult care		20. Second / final consultation in adult care	
	20.1 1 A second consultation alone in adult care is made	<b>87.9%</b>	20.1 1 A second consultation in adult care is made	<b>ND</b>
	21. Feed-back on the second consultation		21. Feed-back on the second consultation	
	21.1 Feedback on the second consultation from patient AND parents is given to the pediatric team to assure that everything went well and as expected	54.5%	21.1 Feedback on the second consultation from patient AND parents is given to the pediatric team to assure that the adherence of patient and his/her family to the adult consultation is satisfactory	<b>80%</b>
<b>ENGAGEMENT PHASE</b>				
20-24	22. Help the patient acquire more autonomy		22. Help the patient acquire more autonomy	
	22.1 Discussion with patient about needs to become more autonomous in her/his daily needs	<b>81.8%</b>	22.1 Discussion with patient about needs to become more autonomous in her/his daily needs	<b>ND</b>
	22.2 Establish means to increase patient's autonomy according to needs	<b>87.9%</b>	22.2 Establish means to increase patient's autonomy according to needs	<b>ND</b>
	23. Regular follow-up in adult care (2checkup consultations or more scheduled)		23. Regular follow-up in adult care (2checkup consultations or more scheduled)	
	23.1 Making sure that a regular checkup consultation schedule is set up.	<b>90.9%</b>	23.1 Making sure that a regular checkup consultation schedule is set up.	<b>ND</b>
	23.2 Making sure that consultations are not missed (especially if not re-scheduled)	<b>93.9%</b>	23.2 Making sure that consultations are not missed (especially if not re-scheduled)	
	24. Discussion about health insurance		24. Discussion about health insurance	
	24.1 Discussing health insurance options (if needed)	<b>87.9%</b>	24.1 Discussing health insurance options (if needed)	<b>ND</b>
	25. Completion of transition plan		25. Completion of transition plan	
	25.1 Patient has a clear educational/professional plan	<b>81.8%</b>	25.1 Patient has a clear educational/professional plan	<b>ND</b>
	25.2 Patient is at ease with self-management	<b>93.9%</b>	25.2 Patient is at ease with self-management	<b>ND</b>
	25.3 Patient is sufficiently autonomous to take care of her/his daily needs	<b>93.9%</b>	25.3 Patient is sufficiently autonomous to take care of her/his daily needs	<b>ND</b>

Table presenting the items that need to be covered within the 3 phases of transition according to 6 age groups; baseline items and baseline agreement percentages and post-consensus meeting items and agreement percentages.

*Percentages in bold are those that reached  $\geq 70\%$  consensus*

\*Proposed ages are only indicative and depend on the level of maturity and development of each patient

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**Figure 1:** the 4 steps of the Delphi-like study

