

Transitional care in the French network for rare malformations of the head, neck and teeth: results of a national survey

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Filière de Santé Maladies Rares des Malformations de la Tête, du Cou et des Dents (TETECOU)



The French rare disease network for malformations of the head, neck and teeth (Filière TETECOU) is composed of 104 expert centers and covers more than 2,100 conditions, often diagnosed before or at birth. The care pathways mostly take place from birth till the end of growth, but variable impact remains during adulthood and some conditions require follow-up: additional surgery, dental issues, psycho-social support, etc.

Purpose

To caracterize patients and caregivers perception, knowledge and needs for the transition period

To caracterize practices and needs of expert healthcare professionals regarding the transition period

To identify targeted actions that could be carried out to improve the transition care



Drafting of two surveys :

- for healthcare professionals of our expert centers - for patients and their caregivers

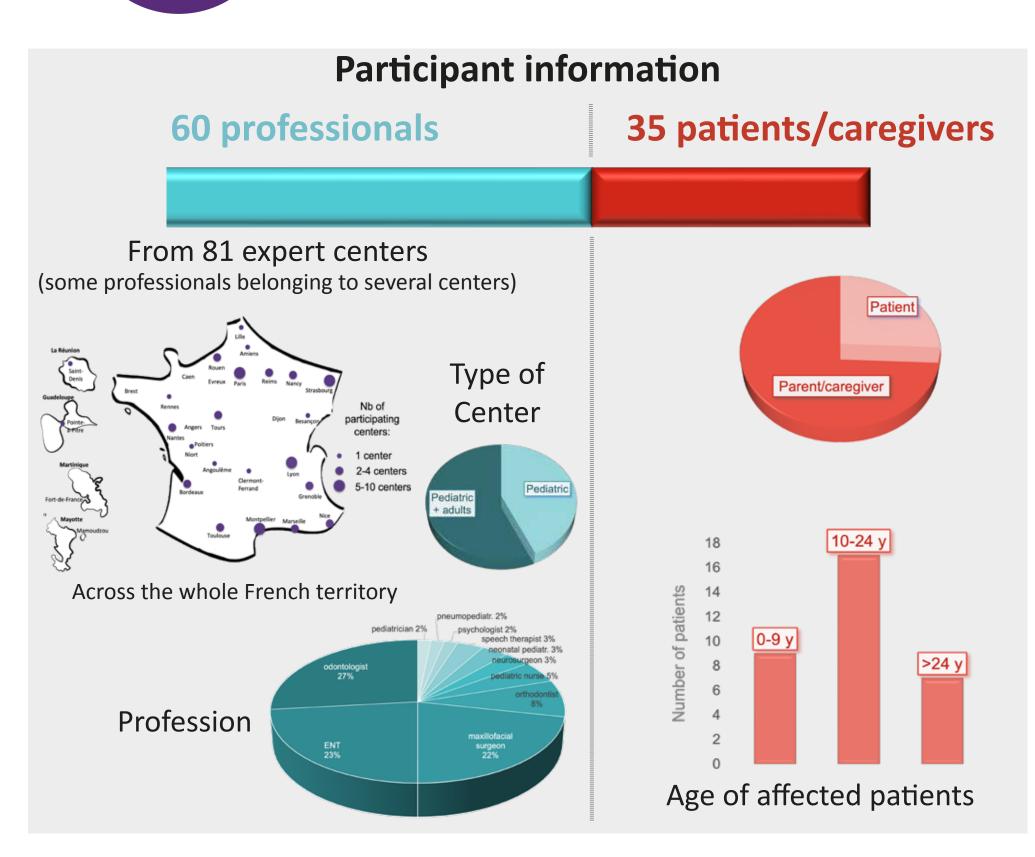
Input from representatives of patient organizations

Circulation by Email campaign and social networks, to healthcare professionals from TETECOU expert centers and partner patient organizations

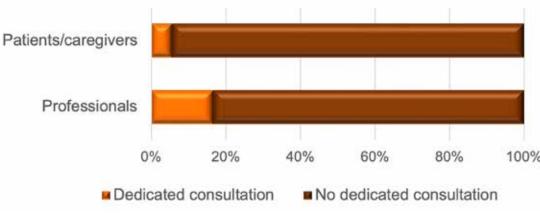
Answers collected from Aug. 2023 to April 2025 Results analysis



nesults



Transition consultation



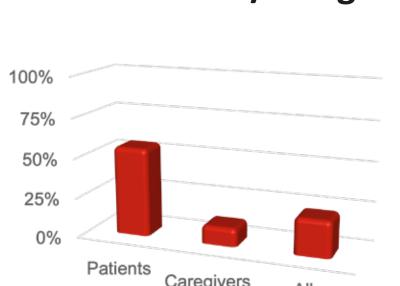
• 94% of patients/caregivers had no dedicated consultation

• 83% of healthcare professionals did not dispense dedicated consultations

Main professionals' reasons for no dedicated consultation: not aware of it (42%), same team for children and adults (19%), no need for adult follow-up (12%)

adults declared having no coordinating professional

Patient/caregiver knowledge of transition



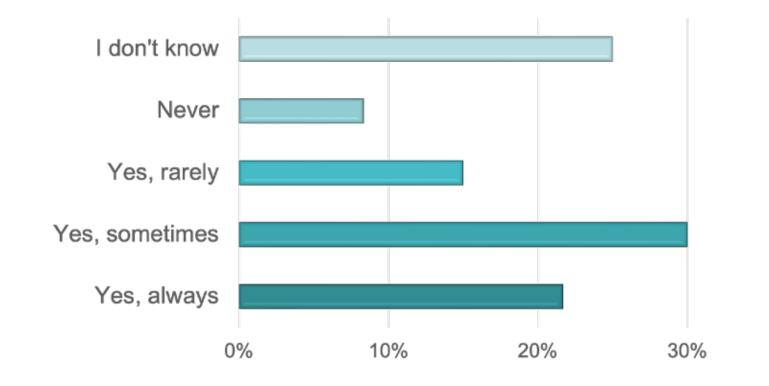
- Overall lack of knowledge about transition (77% do not know about it)
- Only 12 % of caregivers know about transition
- About half of the patients (56%) know about transition

Adult care coordination

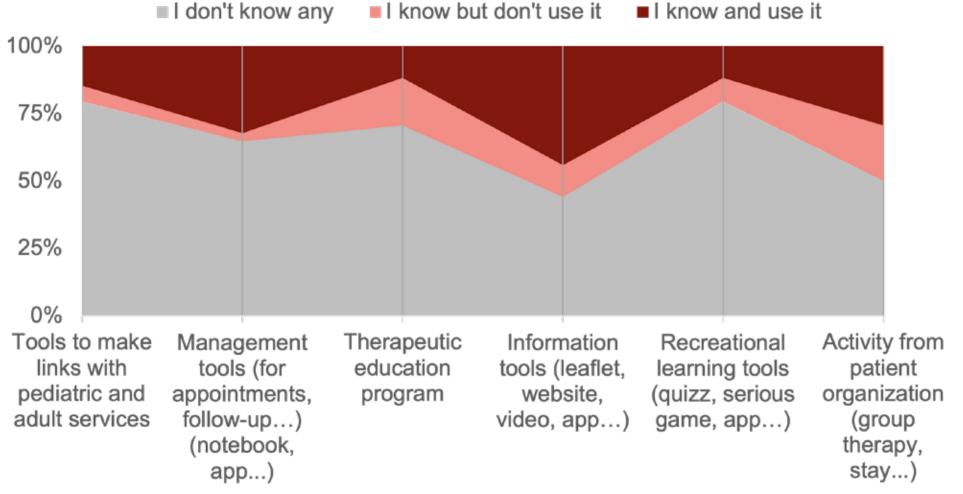
of their patients who have become adults is coordinated by a referring Professionals answers

professional (always 22%, sometimes 30%) • Additional results (data not shown): 75% of the patients who have become

According to professionals from pediatric services, the care of about half



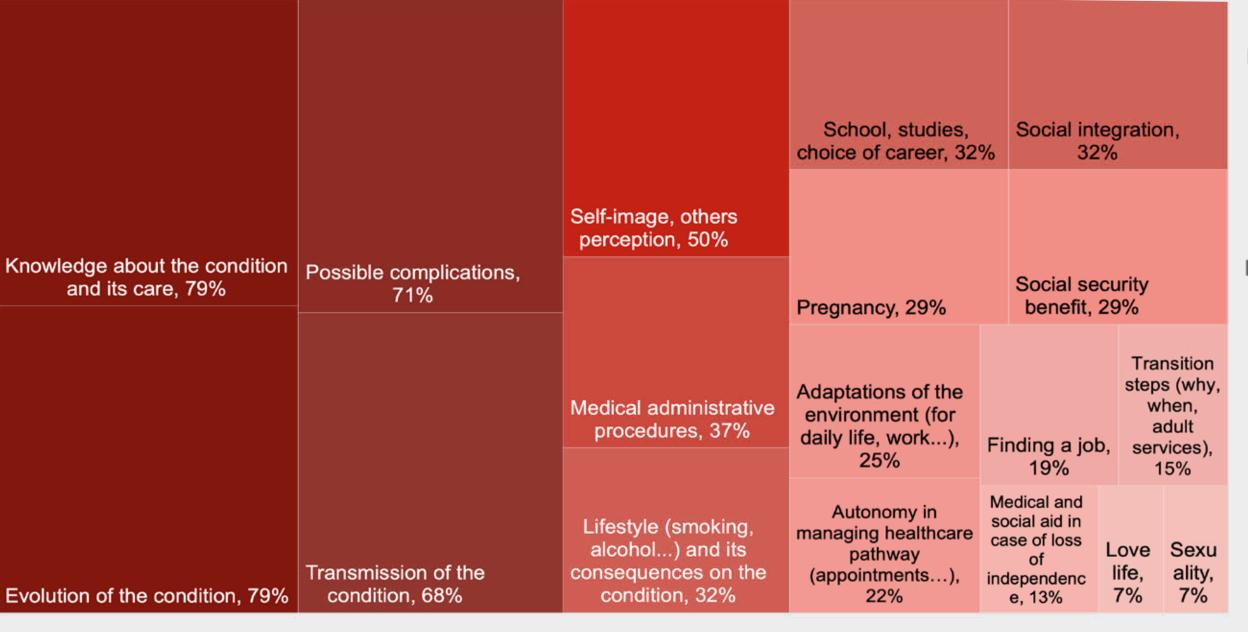
Tools for transitional care used by patients/caregivers

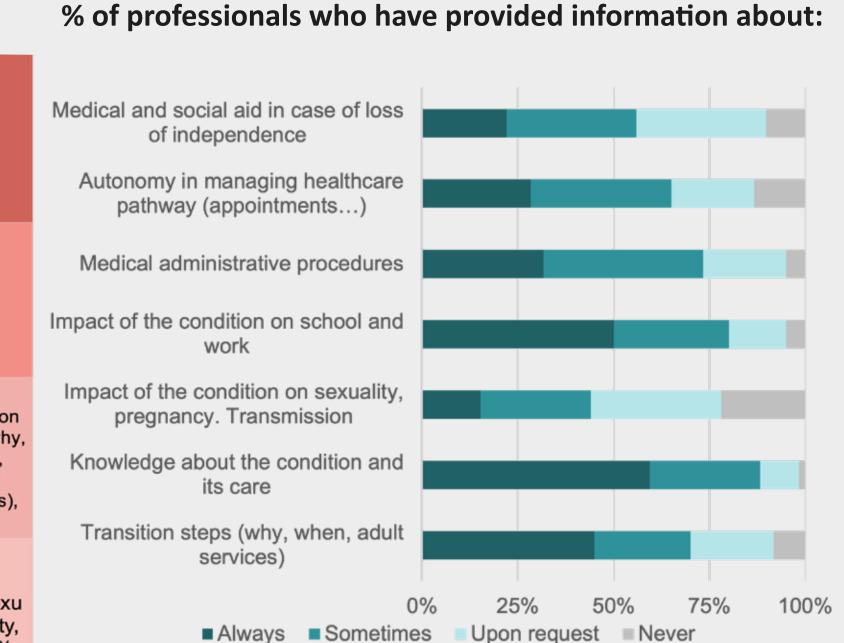


- Knowledge about existing tools is limited
- In general, very few tools are used by patients/caregivers
- Information tools are the most used (44%)
- The limited use of transition tools seems to be correlated to the lack of knowledge about their availability

Very few dedicated transition consultations... but various information delivered on other occasions

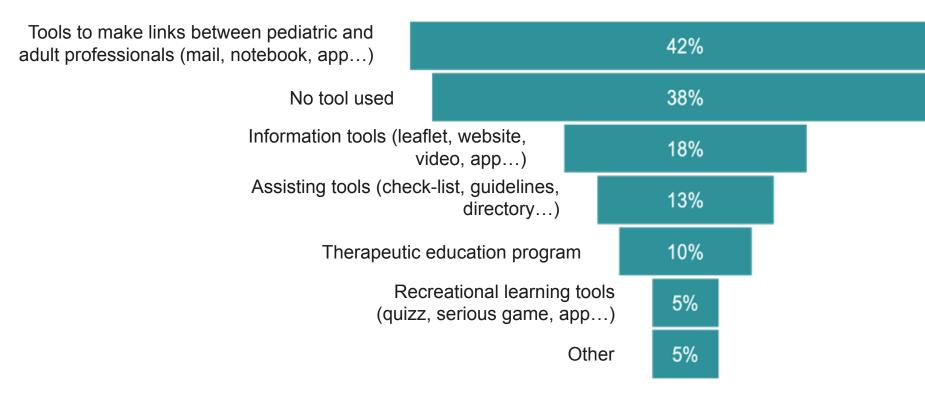






- The rates of information delivered to patients/caregivers for each topic are in good agreement with their expectations (patients/caregivers were also asked on which transition-related topics they would need/would have needed information, data not shown), suggesting no major lack of information
- For all respondents, mostly addressed topic is about knowledge of the condition and its care
- For all the topics listed in the survey, health professionals deliver/have delivered information. Information may be always delivered, sometimes or upon request (depending on the profession of the respondent and the patient/family needs or specific situation)

Tools for transitional care used by professionals

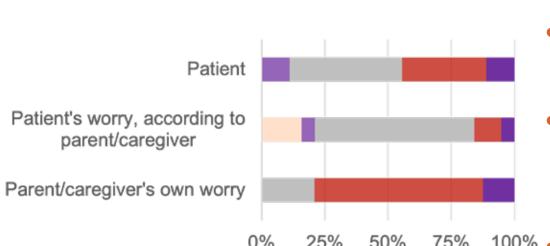


Apprehension of transition to adulthood

Areas of concern

30%

Studies and



According to parents/caregivers

is/was looking forward to it

■ is/did not think about it

Administrative

procedures

Social

integration

■ is/was scared/very scared

■ is/was serene

is/was worried

- 33% of patients were worried, while 44% did not think about it
- A majority of parents were worried themselves (67%); 63% considered their child did not think about it
- 25% 50% 75% 100% These results underline the importance to include parents/caregivers in transitional care pathways

According to patients

integration 32%

Conclusions

For both patients/caregivers and professionals, there is an overall lack of knowledge about the transition process and the available ressources.

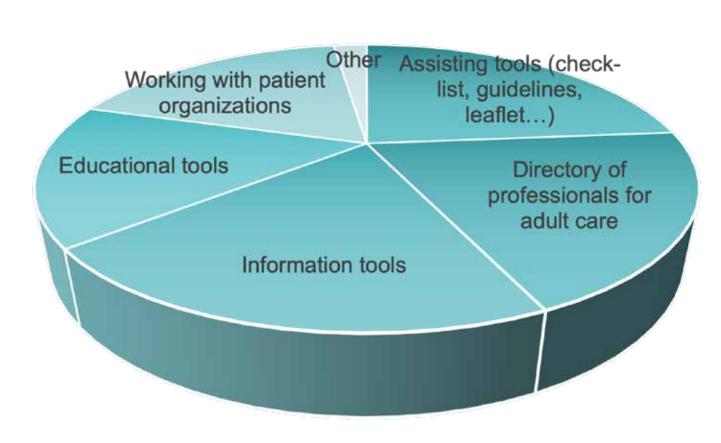
There is a need for additional tools and for more interaction with patient organizations.

These results allowed us to develop new, more targeted, actions. Educational actions have been initiated to raise awareness among professionals, and will continue (seminar, podcast, information on our website...).

Impact of these actions will be evaluated in a future survey.

Beyond these results, the survey itself and its restitution during a TETECOU national workshop have allowed to raise more awareness among health professionals about all the aspects of the transition process and about the available tools.

Professionals would be interested in...



 Very few tools are currently used by professionals, but most of them would be interested in one or several transition tools

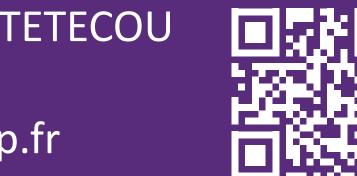
choice and work are the main sources of worry

Health and medical care, studies, career



choice and work are the main sources of worry

• Patients who responded to the survey placed greater emphasis on social integration than parents who responded for their child







Health and

medical care

10%

