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The transition from pediatric to adult healthcare: a leap into the dark?

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Background:

Rheumatological diseases affect over 5 and a half million people in Italy and are diversified into more than 200 pathologies. Rheumatological diseases are also frequent in childhood: in fact, on average 10,000 adolescents in Italy are affected by these pathologies every year, the most common being juvenile idiopathic arthritis. The transition from pediatric to adult healthcare is a crucial moment in an adolescent's developmental direction.

Objectives:

Gather data from Italian caregiver of patients (14-20 y.o.) affected from a rheumatological disease and rheumatic pathology patients (16-30 y.o.) to understand: on the one hand the transition process in terms of informations, on the other hand, the effects of transition on the patients mental health and feelings.

Methods:

A qualitative-quantitative survey was carried out through a questionnaire administered throughout the national territory to a sample of N = 394. The total sample was divided into two targets. Target 1: caregiver (N=308) of rheumatological patients (14-20 y.o.) who made the transition (45,1% , N=139); caregiver of rheumatological patients (14-20 y.o.) who have not made the transition (54,9% , N=169). Target 2: patients of 16-30 y.o. (N=86) with at least one rheumatic pathology who made transition (83,7% , N=72) and not made the transition (16,3% , N=14). The questionnaire was made up of 33 questions, of which 30 were closed and 3 were open. For the administration of the questionnaires, the CAWI (Computer Aided Web Interview) methodology of on-line survey was used. The 394 interviews were carried out from 1 to 31 August 2023.

Results:

Target 1 caregiver: more than 2 out of 10 people (total sample 24.7% , N=76; caregiver of rheumatological patients (14-20 y.o.) who made the transition 19,4% , N=27; caregiver of rheumatological patients (14-20 y.o.) who have not made the transition 29% , N=49) declared that it has no complete information on the transition process. Target 2 patients: the content analysis makes three areas of criticism in reference to the continuity of care: 1) bureaucratic aspects that make the transition process excessively long; 2) insufficient communication and coordination among specialist doctors (pediatricians and adult doctors); 3) emotional, psychological/empathetic aspects: *"I sometimes feel like I'm left alone, left to myself"*.

Conclusion:

The main obstacles that families and patients face in the transition from rheumatologist pediatrician to adult rheumatologist include the lack of clear information about this process, often unstructured communication between the two doctors and the risk of interruptions in therapeutic continuity. In addition, the transition involves psychological and social challenges, such as adaptation to new medical environments and increased responsibility for one's own health.

The research highlights two critical areas that make the transition a path that is not always easy: on the one hand, caregivers declare that they often have incomplete information, on the other, people affected by rheumatological diseases in children, report some difficulty in dealing with specialists from the communicative and empathetic point of view.

References:

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