Adults with Spina Bifida: Transitional Care or leaving patients alone? Two different points of view

The objective of the survey was to evaluate pathways for this rare disease, focusing on the phase of Transitional Care, a delicate period from the childhood to the adolescence and the adult age - and to investigate the meaning and consequences of this transition depending on the different points of view of different professionals: families, paediatricians and other providers of care. A redefinition and reorganization phase, in fact, is in place to face the emerging fact: the increase of the average age of the persons with Spina Bifida.

Two interview forms were structured, for patients and physicians respectively; the items were chosen to facilitate the openness the patients to tell their own living with the illness, describing their pathway not only through the clinical steps list, but also narrating their feelings, fears, achievements, criticisms. The stories were collected in 2010, with full compliance with privacy law, to establish a dialogue with the person.

The primary concern for physicians is the Transitional Care organization, because adults with Spina Bifida represent on average almost 50% of the patients and currently this phase has been not defined and there is a lack of specialized Spina Bifida centres for adults. Spinal Cord Injury (SCI) Unit could be the destination, but our analysis reveals that each Centre is adopting its own solution: 30% of them carry out their transitional care in their Pediatric Centres, 20% in Outpatient's Department for adults with Spina Bifida, 50% and 50% continue to care the patients over eighteen with the same team, although the paediatric background. The reorganization.

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