



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

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Project ANTARES: objectives

The Italian multicentric study called "ANTARES" investigated pathways of patients with Spina Bifida through narrative medicine. The study involved 12 Italian Spina Bifida Centres and 61 stories were collected among persons with Spina Bifida, their carers and physicians.



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The objective of the survey was to evaluate pathways for this rare disease, focusing on the phase of Transitional Care - a delicate changeover from the childhood to the adolescence and the adult age - and to investigate the meaning and consequences of this from the different points of view of patients', 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 and transcribed in presence (in full compliance with privacy law), to establish a dialogue with the person.

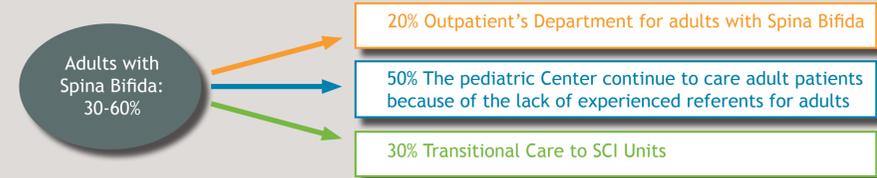
What is Transitional Care?

Transitional Care is defined as a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location. Transitional Care is based on a comprehensive plan of care and the availability of health care practitioners who are well-trained in chronic care and have current information about the patient's goals, preferences, and clinical status. It includes logistical arrangements, education of the patient and family, and coordination among the health professionals involved in the transition. Transitional Care, which encompasses both the sending and the receiving aspects of the transfer, is essential for persons with complex care needs. (Source: *Improving the Quality of Transitional Care for Persons with Complex Care Needs. Journal of the American Geriatrics Society. 2003*)

The Transitional Care program is used also for assisting adolescents and young adult (15-25 years old) with chronic condition to adult healthcare (*American Academy of Pediatrics "A consensus statement on health care transitions for young adults with special health care needs", Pediatrics, 2002 - Betz et al. 2010 - Holmbeck et al. 2010; Sawyer & Macnee 2010*).

The physicians' point of view

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 the Transitional Care to the SCI Units, 20% have established an outpatient's department for adults with Spina Bifida, and 50% continue to care the patients over eighteen with the same team, although the pediatric background:



Most physicians consider their team not prepared to cope with the teenagers and adult people questions, especially regarding sexuality; furthermore, they perceive the difficulties, shyness and embarrassment of families to talk about this topic. Together with the worry for the lack of turnover among experienced providers - when a physician retires, the hospital management often does not replace the competence on caring of Spina Bifida - physicians are wondering about the future of Spina Bifida Centres and their reorganization.

There is a general lack of specialized figures on sexuality, which is faced by our team with a clear inadequacy, although the good intentions, also because patients requirements are often linked neither to paediatric age, nor to adult age

Because of the strong attachment by the families to the paediatric Centres, we report some difficulties in carrying out the Transitional Care to the SCI Units, which generally at the beginning is not accepted; families feel abandoned because, after almost 20 years, they have to change referents, going to a centre with a different organization and a different approach to Spina Bifida. We are trying to formalize the Transitional Care to the local SCI Unit, but currently there is still a dichotomy between the Spina Bifida Centres and the SCI Units, which should increase their attitude towards patients with Spina Bifida

In our paediatric Centre we continue to take care of adults with Spina Bifida because of the lack of experienced referents in the territory; when I will know that there is some physician at disposal, I will be glad to do the Transitional Care

Generally, we expect that families require a counseling on sexology, but this is often delayed and we still receive a few requests. Sexuality is difficult to face for persons with Spina Bifida and their families, they often would like to ask some questions but they are ashamed. To offer better services and give complete answers to adult patients, I think that we have to specialize more on sexology

When patients with Spina Bifida are 18-20 years, they have to refer to different health care professional with new figures, persons are more stimulated to confide their new requirements, especially regarding sexuality. Referring always to the same physicians is a limit for their autonomy. In fact, when persons with Spina Bifida reach 18 years, they are generally less autonomous than they should be

The number of over 18 years patients with Spina Bifida is increasing and we are questioning how to set up an appropriate pathway for them. In particular, we are thinking to organize a Transitional Care to the SCI Units, because when persons with Spina Bifida become adult, they have totally different needs from the paediatric age; furthermore, SCI Units can offer to adults with Spina Bifida training pathway to increase their autonomy

The persons with Spina Bifida's point of view

Patients living with Spina Bifida, on the contrary of physicians, are not well disposed to the Transitional Care, because they prefer to maintain the paediatric referents; changing health centre and physicians is often perceived as a left alone and a possible shock for the family.

Now I'm adult, but I continue to refer to the same physicians, also because I don't know if there are other experienced professionals in my territory; sometimes I think what I'll do when they won't be anymore

I am 51 years old but I continue to refer to this Centre, despite the paediatric context, because in the past I visited many other places, but only here physicians could solve my urological problem, after some not correct surgeries made by Urologists for adults not experienced in Spina Bifida

The doctor is my only real referent for me; he knows me since I was born and he's my reference for everything. He does much more than he must to do, and compensates for the lack of experienced referents. I am 19 years old; until my physician will take care of me, I will continue to refer to this paediatric Centre; when this will not be possible anymore, I will look for a solution

My daughter's physician said to us that we have to prepare for the Transitional Care and I'm worried about this; the Spina Bifida Centre is like our home

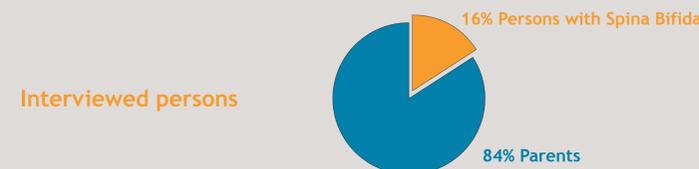
Even if my son has grown up, he needs of a constant reference point, like all our family. I believed that the biggest problems were in the paediatric phase, but now I know that there are many problems during the adolescence as well. When my son will be 18 years old, I want to be oriented, I don't want to looking for new referents blindly

My son is 17 years old. Last year we were at a SCI Unit and I was really satisfied, because physicians could solve his urological problems and he improved his autonomy, but now we have come back at the Spina Bifida Centre, because here there are other persons with Spina Bifida, while at the SCI Unit patients do a different pathway and have different stories from my son

When my son was born, 21 years ago, in a few days I knew all the physicians who are still taking care of him; the Centre is the same and this is reassuring. For adolescents with Spina Bifida the continuity of care is important, the situation is already too hard for them

Only 22% of adults with Spina Bifida report to have been changed their physicians after a Transitional Care phase, 45% refer to the same paediatric team and 33% to the same paediatric Centre but with some new figures.

This is not the only "maternage" revealed by families. Although the 62% of the subjects with Spina Bifida were between 16-50 years old, in fact, in the 84% of the interviews only parents were involved, giving their witness instead of their sons' and daughters' one; this might be a sign of a hyper protective which does not foster the young patients with Spina Bifida towards autonomy. A double maternage is revealed, as a matrioscol wooden Russian doll, one carried out by the reference centre, one by the family.



Final remarks

From the interviews, two points of view emerge, different between physicians and persons with Spina Bifida. Into the Spina Bifida Centres the physicians, aware of the increasing of adults with Spina Bifida (almost 50% of the patients) and their new requirements, are questioning about the future of the centres, the need of new organizational models and new expertise. The Transitional Care to SCI Units seem to represent the better answer to these changes (for 69% of them). On the contrary, persons with Spina Bifida and their families reveal to be not well disposed to change referents, although more competent on adult age, showing a strong "maternage" both with the paediatric Centre and the family. Are the two points of view incompatible? Is the Transitional Care to SCI Units the right answer to adults with Spina Bifida requirements? And how to conciliate the persons' expectations with the physicians' ones? The question is open.

Persons with Spina Bifida can't be totally cared, but many things can be done to improve the quality of their life

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