

Concluding Remarks

A clear link has been made between psychological factors and recurrent headache in children with shunted hydrocephalus. Effective management requires a clear understanding of all factors which could contribute to headache presentation, and psychosomatic disorder cannot be ruled out.

References

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The “Failures” of Spina Bifida Transdisciplinary Care

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Introduction

The transdisciplinary team model, initially created for people with cerebral palsy, has been recognized as the medical standard for complex multi-disabilities such as those occurring in spina bifida (4). The myelomeningocele (MMC) patients have multiple neurological impairments. This fact places them at high risk for secondary (mostly preventable) morbidities such as urological problems, kidney disease, pressure ulcers and orthopaedic deformities, in addition to the neurosurgical complications. This leads to the involvement of many different specialists in the care of people with spina bifida (SB), at a tertiary level.

According to the literature about team models, patient outcome seems to be highly related to team collaboration (4), which can be relatively limited in the multidisciplinary model, where the role of each team member is clearly defined; when professionals act independently, fragmented care can easily result because of poor communication. The transdisciplinary approach promotes an integrated assessment and develops a unified treatment plan that is based on the child's needs and is jointly carried out by all team members with parental involvement. The parents and older patients should be considered essential members of the team and they must be educated about different SB pathologies, potential problems and goals of treatment, to improve compliance with programmes, anticipate secondary disabilities and fully participate in decision-making.

However, from our experience of running a transdisciplinary spina bifida clinic, providing completely free care, there are always a few children who are prone to more complications than peers, with a similar condition. Our goal in this study is to identify

under a global view common risk factors among children for whom things go wrong and to define an integrated strategy for these and future cases, in order to anticipate and prevent complications.

Material and Methods

A total population of 109 children with neural tube defects is followed up in our Clinic, in a central paediatric hospital, most of them from birth onwards. Among the 96 MMC patients, aged 3 months to 18 years, mean age 9.7 years, we identified 13 “problematic” children. We considered “problematic” the children who presented with preventable secondary disabilities, with serious compromise of the quality of life and even life expectancy. We excluded the neurosurgical problems, such as complications of shunted hydrocephalus and of tethered cord, because in many cases it is difficult to establish the degree to which these conditions are preventable.

Three of the 13 problematic children have renal failure and are on haemodialysis, a fourth has undergone a renal transplant, 7 have multiple bilateral renal scars, with a poor renal function and one of these has also suffered a foot amputation, and 2 have recurrent skin pressure ulcers, one at risk of a foot amputation. Data concerning age, sex, race, location, MMC level, frequency of hospital admissions and total length of hospitalisation per year in the last 3 years, single parent families, family conflicts, poverty, low education level of parents, appointment missing and primary care health support, were obtained from the clinical records of all the MMC patients. A comparative study was conducted between the “problem group” and the other 83 MMC patients of the Clinic, used as reference group.

Results

In 13 children with preventable complications, ages ranged from 3 to 18 years, with a mean age of 10.2 years, similar to the reference group (10.5 years). The other results concerning the two groups are listed in Table 1, with significant values indicated.

Discussion

Over the last 20 years, improvement in the management of SB patients has greatly reduced morbidity, changing the previous ominous long-term prognosis for a large subset of this population (1). However, among our 96 MMC children 13.5% present with serious preventable renal and dermatological secondary complications, even though they have been followed since birth by a transdisciplinary experienced, motivated and stable team, in a tertiary centre. Definitely there are gaps in our services due to which some children fall through the net. By becoming aware of these gaps we will limit the failures in future. From our experience we had anticipated some common features among the problematic children, such as poverty, single parent families and family conflicts; the same features proved to be statistically significant in this study. Appointment missing, high frequency of hospital admissions and longer stays were also significant and must be interpreted as an alarm sign from these children.

Table 1 Comparison between the two groups

Characteristics	"Problematic" group (n = 13)		Reference group (n = 83)	
	n	%	n	%
Gender	11 girls	85	47 girls	56
Race (black children)	1	8	7	8
Location distance (> 100 km)	4	31	22	26
MMC level (< L ₃)	6	46	42	51
Poverty***	10	77	17	20
Single parent family**	6	46	12	14
Parental conflicts**	3	23	3	4
Parental low academic status	7	54	40	48
Missed appointments (> 25%/year)***	6	46	12	14
Number of admissions > 3/year**	8	61	16	19
Length of hospital stay > 20 days/year**	8	61	16	19
Primary care addressed support	0	0	3	4

χ^2 test, 1 d.f. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

A structured family, with concerned parents, plays an important role in the continuity and quality of follow-up (3). With family dysfunction and poverty not enough energy remains for parents, especially the mother, to dedicate to the highly complex needs of the SB child. They need help at the community level, where the patient spends most of his time and many of his problems have to be detected and correctly oriented. The limited utilization of primary health care close to home is an issue generally recognized (2) and difficult to solve everywhere. Our team organized several meetings with local doctors and nurses, giving them information about SB and offering training, without significant results. The low prevalence and usually high severity of the cases do not attract the local health professionals to SB.

If parents are demanding and the family is structured they always get some help from the community-providers and manage the services offered according to the SB team instructions, usually with good results for the child. If the family presents with the risk factors mentioned above, the team must immediately outline a tailored strategy for that child.

After some experiments without success, we have just began another model: someone in the team, generally a nurse, will be directly responsible for the suspected child, visiting the family regularly in the community and surveying the quality of care. If our initial suspicions are confirmed and the family does not function as a protective environment, then someone in the community interested in the child and accepted by the family must be trained in SB issues by the child guardian of the team. It can be a relative, a friend, a neighbour or a volunteer; the essential thing is to find someone who will guarantee responsibility and continuity. The designated team professional will make the linkage between the community-provider and the Clinic by exchanging knowledge and better addressing the needs of the child and the family.

We are convinced that this is a valid alternative for an effective support of the most vulnerable SB patients and families in regions with poor primary health care anchorage. This model will allow an early identification of medical complications and opportune referral, preventing the enormous burden that the increase in morbidity represents both for the patient, the family and the health care system (3).

Conclusions

Transdisciplinary teams, even with high standards of care, may fail with some SB children, which is not acceptable anymore. In our case 13.5% of the children, most coming from poor and dysfunctional families, have preventable complications, with high costs for everybody. In these cases a reinforcement between the team and the community must be made, with a member of the team being directly responsible for the child. This professional must become familiar with the community and find someone in the child's surroundings capable enough to be trained in SB issues. A continuous exchange of information between these two persons, rapidly expanded to the rest of the team, will guarantee an adequate and consistent care of the child.

References

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