



ORIGINAL ARTICLE

Tethered cord in patients affected by anorectal malformations: a survey from the ARM-Net Consortium

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Abstract

Purpose The goal of this study was to determine the degree of consensus in the management of spinal cord tethering (TC) in patients with anorectal malformation (ARM) in a large cohort of European pediatric centers.

Methods A survey was sent to pediatric surgeons (one per center) members of the ARM-Net Consortium.

Results Twenty-four (86%) from ten different countries completed the survey. Overall prevalence of TC was: 21% unknown, 46% below 15, and 29% between 15 and 30%. Ninety-six agreed on screening all patients for TC regardless the type of ARM and 79% start screening at birth. Responses varied in TC definition and diagnostic

tools. Fifty percent of respondents prefer ultrasound (US), 21% indicate either US or magnetic resonance (MRI) based on a pre-defined risk of presenting TC, and 21% perform both. Discrepancy exists in complementary test: 82% carry out urodynamic studies (UDS) and only 37% perform somatosensory-evoked potentials (SSEP). Prophylactic untethering is performed in only two centers (8%).

Conclusions Survey results support TC screening in all patients with ARM and conservative management of TC. There is discrepancy in the definition of TC, screening tools, and complementary test. Protocols should be developed to avoid such variability in management.

Keywords Anorectal malformation · Tethered cord · Neurosurgery · Arm-Net Consortium

Members of ARM-Net Consortium are listed in acknowledgements.

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Introduction

Patients with anorectal malformation (ARM) may present associated congenital defects, including spinal dysraphism with cord tethering (TC). This is an anatomical condition consisting in the fixation of the lower end of the spinal cord. During growth and development, the increased traction on the tethered cord can result in progressive symptoms and signs involving motor-sensory, orthopaedic, urinary, and bowel function [1–3], leading to the tethered cord syndrome. Orthopaedic symptoms can present as weakness or atrophy, abnormal reflexes, pain in the back or legs, sensibility disorders, deformities, and gait abnormalities. Urinary involvement can include incontinence or urge due to neurogenic bladder, while bowel symptoms can be soiling and fecal accidents. As urinary and fecal symptoms are frequent encountered in patients with ARM also without TC, it is difficult to conclude whether they are

secondary to TC or to ARM itself. Therefore, the impact of TC on functional prognosis remains unclear in ARM patients [4–8]. Moreover, the definition and management of TC are still extremely variable among pediatric surgeons [2, 5, 7–10].

The purpose of this study was to determine the degree of consensus in the current management of TC in a large cohort of European pediatric centers and provide a basic assumption to deliver a standardized care for these patients.

Methods

A survey was sent in February 2017 to one pediatric surgeon per each center member of the ARM-Net Consortium ([Appendix](#)). Survey questions pertained to the definition of TC, prevalence, screening, complementary studies, and management. Results are presented as percentages. Consensus was arbitrarily defined if more than 70% of respondents were in agreement.

Results

The results of the questionnaire are summarized in Table 1. Among eligible surgeons (one per center), 24 (86%) from 10 different countries completed the survey. Responses varied substantially in TC definition. Thirty-nine percent defined TC as any conus ending below the L2–L3 intervertebral disc level and 30% as any conus ending below mid-L2 vertebral body. Figure 1 shows the answers to the question “How do you define tethered cord?”

The overall prevalence of TC among ARM patients was unknown by 21%, below 15% by 46%, and between 15 and 30% by 29% of respondents.

All respondents but one (96%) agreed on screening all patients for TC regardless the type of ARM and most of them start screening at birth (79%). However, diagnostic tools for screening varied widely. Figure 2 shows the answers to the question “If you screen your patients, what diagnostic tool do you use as first line of screening?” Fifty percent of respondents prefer ultrasound imaging (US), and nothing else, if it is normal, 21% perform both US and magnetic resonance (MRI) and another 21% indicate either US or MRI based on a pre-defined risk of presenting TC and the remain 8% perform MRI. Seventy-nine percent of respondents have a pediatric radiologist specialized in ARM in their own center.

Considering complementary test performed after the diagnosis of TC, the respondents reached consensus (82%) on carrying out urodynamic studies (UDS) and on avoiding manometry (87%). As far as somatosensory-evoked potentials (SSEP) are concerned, only 37% of respondents believe that it is a useful test.

A majority of respondents (92%) refer the patient to a pediatric neurosurgeon: 29% with no previous discussion, 37% after discussing the patient with the neurosurgeon, and 25% after presenting the patient in multidisciplinary team meetings that include a neurosurgeon.

Only two centers (8%) perform untethering in asymptomatic patients upon neurosurgeon’s indication, while none of the pediatric surgeons surveyed suggest prophylactic neurosurgery. The vast majority of respondents (92%) perform neurosurgery only when symptoms develop or worsen (motor sensory, bladder, or bowel dysfunction). The main arguments against neurosurgical approach are: not all the patients with anatomic TC will develop symptoms (100% of respondents), it is unproved that symptoms will worsen if the cord is left tethered (56%), some patients operated at an early stage may undergo re-tethering as they

Table 1 Summary of the survey results

| TC definition | 13% L1–L2 | 30% L2 mid-body | 39% L2–L3 | 9% L3 mid-body |
|---|--------------|-----------------|----------------|----------------|
| TC prevalence | 21% unknown | 46% < 15% | 29% 15–30% | 4% 30–45% |
| Screening for TC | 96% yes | 4% no | | |
| Age of screen | 79% at birth | 12% 1–6 months | 8% 6–24 months | |
| Screening tool | 50% US | 21% US and MRI | 21% US or MRI | 8% MRI |
| Pediatric radiologist dedicated to ARM | 79% yes | 21% no | | |
| USD after TC diagnosis | 82% yes | 18% no | | |
| Manometry after TC diagnosis | 17% yes | 83% no | | |
| SSEP after TC diagnosis | 37% yes | 63% no | | |
| Pediatric surgeon advocate prophylactic untethering | 0% yes | 100% no | | |
| Neurosurgeon advocate prophylactic untethering | 8% yes | 92% no | | |
| Centers performing prophylactic untethering | 8% yes | 92% no | | |

Fig. 1 Graph shows the response to the question “How do you define tethered cord?”

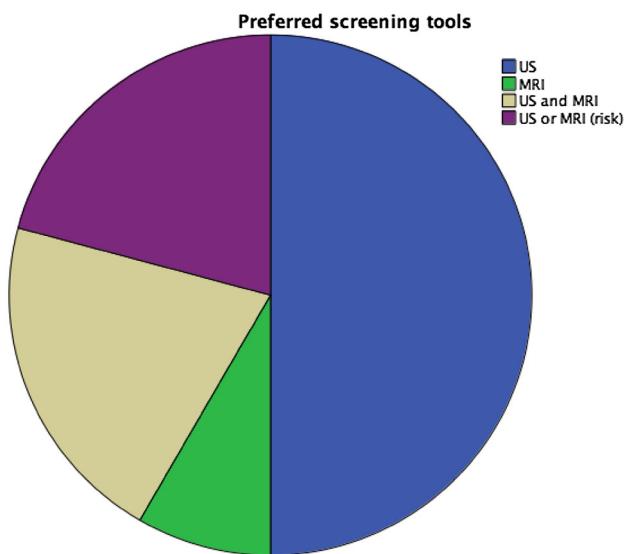
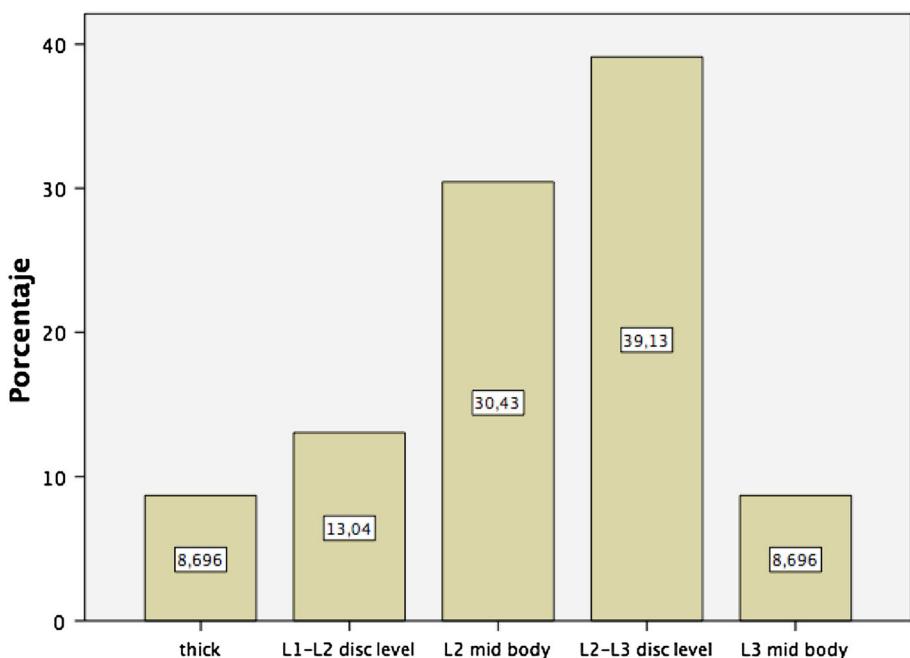


Fig. 2 Graph shows the response to the question “If you screen your patients, what diagnostic tool do you use as first line of screening?”

grow (56%), and untethering may result in complications (13%).

Discussion

TC is a well-known anomaly associated with ARM. Routine screening for TC in ARM patients is being widespread and implemented as part of ARM protocols in most centers [2, 8] leading to an increasing reports of TC associated with ARM [9]. The clinical significance of such anomaly

remains unclear and the question if and how to handle this condition remains unsolved. There is a general consensus on surgical treatment of symptomatic patients [1–3, 9], but the role of prophylactic untethering is still a subject of debate [3, 8, 10, 11]. Moreover, different opinions exist in many other issues regarding TC, including definition, incidence, and management, both among pediatric surgeons and pediatric neurosurgeons.

Our survey highlights a controversy in the definition of TC. It has been suggested that any conus ending at or above the L2–L3 inter-space should be considered as a normal level and a filum terminale <2 mm as a normal thickness [1, 8, 12, 13]. This was, indeed, the definition accepted by only 39% of respondents. Other definitions are reported in the literature as among the respondents. Di Cesare [5] defines TC when the conus lies below L1 and L2 inter-space, Taskinen et al. [14] and Frainey [15] consider as “low-lying” a conus below the midpoint of L2 vertebral body and for van den Hondel [2] when the conus is below the body of L3. Since TC is a morphological definition, we should be able to come out with a validated single definition that allows surgeons all over the world to compare their data and conduct research established on common ground.

In the present survey, the prevalence of TC shows a wide range similar to previous reports in the literature (10–60%) [3, 8]. This could be explained, as in the literature, by the different screening tools or definitions that are used. The evident association between TC and ARM [10] supports the recommendation for TC screening in all patients with ARM.

The imaging tool most used for screening was US, chosen as a screening test in the neonatal period by half of respondents. It is non-invasive, less expensive, quick, dynamic, and does not require sedation [11, 16, 17]. Yet, some authors do not consider US a good screening test by reason of a lower sensitivity [2, 18] which could underestimate the true prevalence of TC [2, 8]. MRI is considered the gold standard to detect spinal dysraphisms [5, 11, 19] because of its high sensitivity [20, 21]. Moreover, it can show other concomitant anomalies (gynaecological, genito-urinary, and pelvic masses) and can provide a postoperative assessment of muscles complex, position of the rectum, interposed fat, and occurrence of posterior urethral diverticulum in males [13, 22, 23]. However, it is expensive, less widely available and requires general anaesthesia. Independent from the preferred imaging tool, the involvement of a pediatric radiologist and a pediatric neurosurgeon with special interest for ARM is important, since they play a key role in the multidisciplinary team.

In agreement with other studies, most of respondents support UDS as an additional investigation after TC is diagnosed [15, 17, 24, 25]. The role of SSEP is not clearly established yet. Suppiej et al. [26] studied the use of SSEP in children with TC complicating ARM. They classified 20 patients based on SSEP and UDS results. The first group ("stable") included nine patients with normal SSEP and normal UDS findings. The second group ("possible candidates" for surgery) included eight patients with mildly abnormal SSEP or UDS and the third group ("operated") included three patients with clearly abnormal SSEP or UDS. They concluded that the combined use of SSEP and UDS could be useful in detecting neurological deterioration before clinical evidence occurs. Further studies are still needed.

Questions regarding the clinical significance and natural history of TC remain unclear. Not all patients with anatomic cord tethering develop symptoms [1]. Patients with ARM seem to be a special subgroup and their natural history needs to be investigated as it seems to be quite different from TC patients born without ARM [5, 7, 8]. Di Cesare et al. [5] report that none of the patients left tethered develop complications due to the progression of the neurospinal condition. Taskinen et al. [14] analysed the effect of spinal cord anomalies on lower urinary tract function in patients with ARM and concluded that progressive symptoms were not seen in most patients. Kyrlund et al. [7] compared outcomes in 64 patients with ARM with and without normal spinal cord. Their results suggest that the natural history of spinal cord anomalies was benign and stable. Tuuha et al. [9] followed up for 2.7 years a series of ARM patients with TC and no deterioration of neuro-motor, urinary, and bowel function was noted.

Surgical untethering is generally performed depending on neurosurgeon's preference [1, 3, 11, 27, 28]. Lew [1] supports surgery only when progressive or new-onset symptoms occur. Similarly, Kim et al. [19] in their series of 120 patients performed surgery only in 26 symptomatic cases excluding those asymptomatic patients presenting a low conus medullaris. On the contrary, Golonka [20] and Teo [11] recommend prophylactic untethering.

In the literature, the majority of neurosurgeons suggest prophylactic surgery, while most of pediatric surgeons recommend surgery only when signs or symptoms appear [5, 26, 28]. Clinical outcome after untethering in both symptomatic and asymptomatic patients with ARM appears to be quite variable and unclear [9]. After untethering, improvement of sensory-motor symptoms is described, but minimal impact on urinary or bowel symptoms has been observed [3, 9, 11, 19, 27]. Levitt et al. [10] describe 27 patients with TC and ARM. Eighteen underwent surgical untethering, and six of them were asymptomatic. They found no significant postoperative changes in urinary or fecal continence. Similarly, Tuuha [9] and Uchida [3] observed that bowel and urinary functions remain unchanged after neurosurgery and Golonka [20], even favouring prophylactic surgery, and concluded that fecal and urinary incontinence are unlikely to be improved after surgery. Altogether, these reports make the need of prophylactic surgery unclear in ARM patients and a wait-and-see approach seems to be acceptable in the absence of sensory-motor symptoms, as advocated by all pediatric surgeons in the survey.

In conclusion, wide variation regarding the diagnosis and management of TC in ARM patients exists among pediatric surgeons specialized in the care of these patients. The ARM-Net pediatric surgeons reach an agreement on (1) screening for TC in all patients affected by ARM at birth, (2) performing UDS after the diagnosis of TC as part of the protocol, (3) promoting a wait-and-see approach to a TC avoiding prophylactic surgery, and (4) requiring a multidisciplinary approach with cooperation of pediatric radiologist specialized neurosurgeon dedicated to ARM. Shared protocols on definition, screening, complimentary diagnostic studies, and neurosurgical indications among institutions are needed and such projects are being undertaken by the Arm-Net Consortium.

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Appendix: Current ARM-Net institutions

| Name | Institution | Country |
|----------------|--|-------------|
| Aminoff | AIMAR (patient organization) | Italy |
| Bagolan | Ospedale Bambino Gesù-Roma-Ped. Surgery | Italy |
| De Blaauw | Radboudumc Nijmegen | Netherlands |
| Deluggi | Kepler Universitätsklinikum GmbH-Linz | Austria |
| Fanjul | Hospital Gregorio Maranon-Madrid | Spain |
| Fascetti Leon | University of Padua-Pediatric surgery | Italy |
| García | University Hospital 12 de Octubre, Madrid | Spain |
| Giné | Hospital Vall d'Hebron-Barcellona | Spain |
| Giuliani | St.George's University Hospitals NHS Foundation Trust-London | UK |
| Grano | University Sapienza-Rome | Italy |
| Grasshoff-Derr | Buergerhospital and Clementine Children Hospital-Frankfurt | Germany |
| Haanen | VA (patient organization) | Netherlands |
| Holland-Cunz | University Children's Hospital, Basel | Switzerland |
| Jenetzky | DKFZ-Uni Heidelberg | Germany |
| Lacher | Universitätsklinikum Leipzig | Germany |
| Leva | Policlinico Milano-Pediatric Surgery | Italy |
| Lisi | Santo Spirito" Civil Hospital of Pescara | Italy |
| Makedonsky | Children's Hospital Dnepropetrovsk | Ukraine |
| Marcelis | Radboudumc Nijmegen | Netherlands |
| Midrio | Ospedale Ca' Foncello, Treviso | Italy |

| | | |
|---------------|--|-------------|
| Miserez | UZ Leuven-Dept. of Abdominal Surgery | Belgium |
| Ozen | Gazi University Faculty of Medicine Department of Pediatric Surgery Ankara | Turkey |
| Percin | Gazi University Faculty of Medicine Department of Medical Genetics | Turkey |
| Reutter | Cure-Net University of Bonn | Germany |
| Rohleder | Universitat Medizin Mainz | Germany |
| Samuk | Department of Pediatric and Adolescent Surgery, Schneider Children's Medical Center-Petach Tikva | Israel |
| Schmiedeke | Klinikum Bremen Mitte | Germany |
| Schwarzer | SoMA e.V.-Munich (patient organization) | Germany |
| Sloots | Sophia Children's Hospital-Erasmus Medical Centre Rotterdam | Netherlands |
| Stenström | Lund University, Skane University Hospital | Sweden |
| Till | Universitäts Klinik fur Kinder-Graz | Austria |
| Van der Steeg | Children's Hospital AMC and VU University | Netherlands |
| Van Rooij | Radboudumc Nijmegen, dept Health Evidence | Netherlands |
| Volk | Klinik für Chirurgie, Universitätsklinik Heidelberg | Germany |
| Wester | Department of Pediatric Surgery, Karolinska University Hospital | Sweden |
| Zwink | DKFZ-Uni Heidelberg | Germany |

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