



HOSPICE PEDIATRICO-AZIENDA OSPEDALE UNIVERSITA' DI
PADOVA
DIPARTIMENTO DI SALUTE DELLA DONNA E DEL BAMBINO,
CENTRO REGIONALE VENETO DI TERAPIA ANTALGICA E CURE
PALLIATIVE PEDIATRICHE

Sport in Pediatric Palliative Care

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**5TH MARUZZA
INTERNATIONAL
CONGRESS
ON PAEDIATRIC PALLIATIVE CARE**





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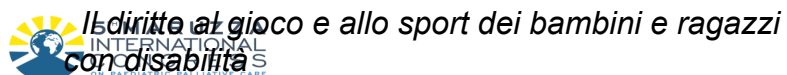
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Background

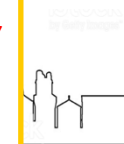
- ✓ **Global guidelines*** recommend inclusive sporting activity for people with disabilities, but scientific evidence on sport activity in pediatric palliative care (PPC) is still limited.
- ✓ We conducted an **pilot study** to describe the sports experience of children followed by our PPC center.

*Convention on the Right of Persons with Disabilities 2016



Methods

- ✓ A preliminary survey to identify children followed by our center who practice sport was conducted in March 2020. All children practicing sport were included in the study.
- ✓ An **online ad hoc questionnaire** was administered to children (when able to respond) and caregivers.
- ✓ Physicians completed **ICF-CY scales** ("Body Function" and "Activity and Participation") to



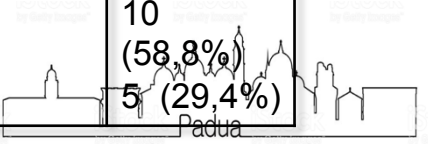


Results

177
 children followed by
 our PPC center

17
 currently practice
 sports (9.6%)
 Age (mean; range): 12 yo; 6-18

Population characteristics	Cases (%)
Sex	
• Male	11
• Female	(64,7%) 6 (35.3%)
Diagnosis	
• Neuromuscular diseases	
• Miopathy	9 (52,9%)
• Central Hypoventilatory syndrome	4 (23,5%)
• Charge Syndrome	2 (11,8%)
• Neurological impairment without diagnosis	1 (5,9%) 1 (5,9%)
Disability	
• Physical	15
• Cognitive	(88,2%)
• Sensory impairment	0
• Both physical and cognitive	0
• Both physical and visual	1 (5,9%) 1 (5,9%)
Medical needs	
• Thracheostomy	
• Nocturnal non invasive ventilation	2 (11,8%)
• Enteral nutrition	10
	(58,8%)
	5 (29,4%)





ICF-CY

severity scales						
0 - no problem	1 - mild problem	2 - moderate problem	3 - severe problem	4 - total disability	9 - not applicable	
ACTIVITIES AND PARTICIPATION						
	severity scales					
	0	1	2	3	4	9
d230 Carrying out daily routine	12	3	1	0	1	0
d240 Handling stress and other psychological demands	0	11	4	1	0	1
d410 Changing basic body position	3	3	2	7	2	0
d415 Maintaining a body position	5	2	4	5	1	0
d420 Transferring oneself						
Moving from one surface	5	1	1	4	6	0
d450 (G) Walking	2	1	1	2	11	0
d455 (G) Moving around	2	3	3	3	6	0
d465 Moving around using equipment	16	0	0	0	1	0
d470 Using transportation	16	1	0	0	0	0
d510 Washing oneself	4	2	2	8	1	0
d520 Caring for body parts	4	0	4	8	1	0
d530 Toileting	3	2	1	9	2	0
d540 Dressing	2	2	2	11	0	0
d550 Eating	6	5	3	3	0	0
d570 Looking after one's health	0	14	0	1	2	0
d640 Doing housework	2	0	2	8	5	0
d660 Assisting others	0	0	0	0	0	17
d710 Basic interpersonal interactions	14	1	0	1	1	0
d770 Intimate relationships	0	0	0	0	0	17

BODY FUNCTIONS	severity scales					
	0	1	2	3	4	9
b130 Energy and Drive Functions	8	7	1	1	0	0
b134 Sleep functions	4	8	4	1	0	0
b152 Emotional functions	13	2	0	0	2	0
b280 Sensation of Pain	15	2	0	0	0	0
b455 Exercise tolerance functions	1	1	1	8	6	0
b620 Urinary functions	13	3	1	0	0	0
b640 Sexual functions	0	0	0	0	0	17
b710 Mobility of joint functions	4	3	7	3	0	0
b730 Muscle power functions	0	0	0	0	0	0

✓ 95% have normal or mild impaired

- cognitive status**
- ✓ 88% have motor disabilities
 - ✓ 82% have no problem in interpersonal interactions
 - ✓ 70% need assistance for daily care
 - ✓ 66% do not walk
 - ✓ 94% are able to move around with





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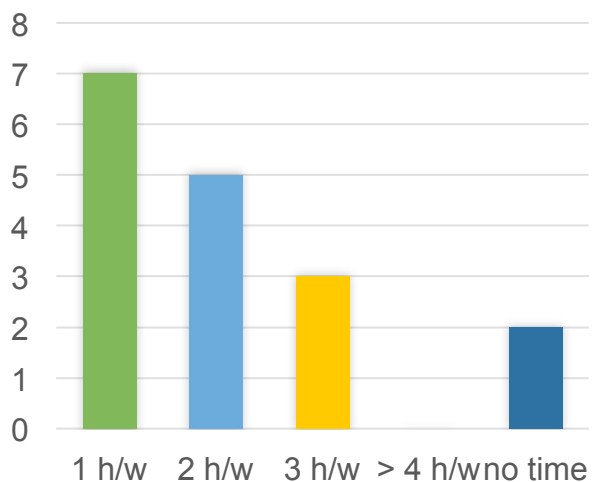
Sport in Pediatric Palliative Care

Results

Children practicing sport...

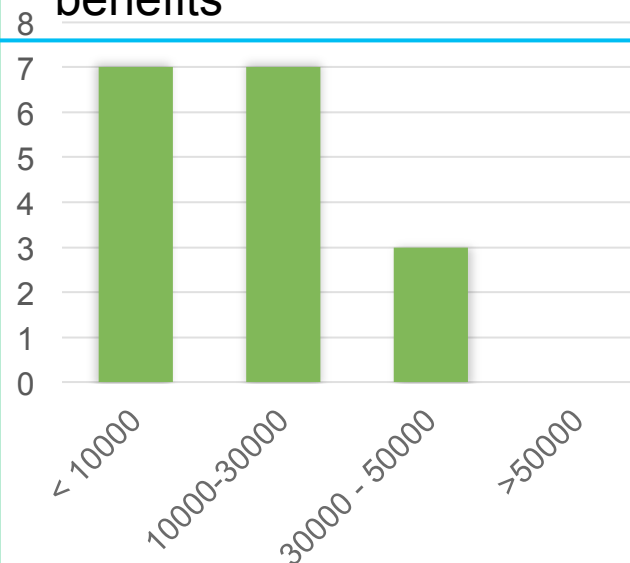
- ✓ 100% attend **school**
- ✓ 88% undergo **physiotherapy** weekly

PHYSIOTHERAPY (HOURS/WEEK)



Family of children practicing sport...

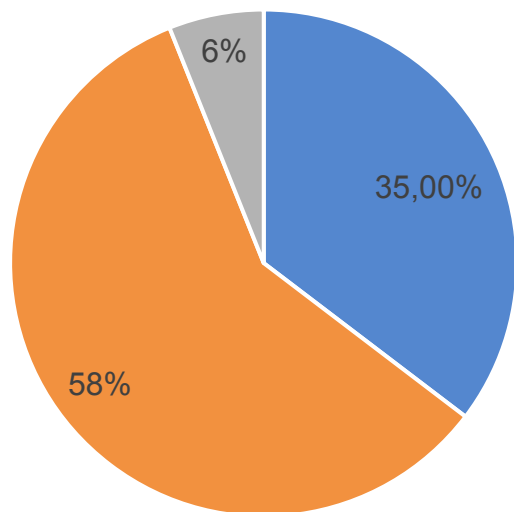
- ✓ 82.3% have low-moderate income
- ✓ 88% receive state economic benefits





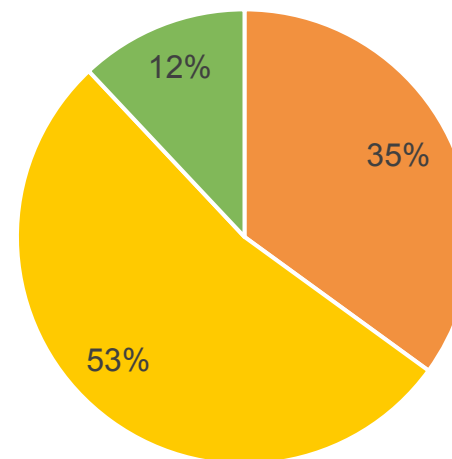
Results

Who suggested to practice sport



■ children ■ parents ■ health care providers

How do you find sport opportunities?

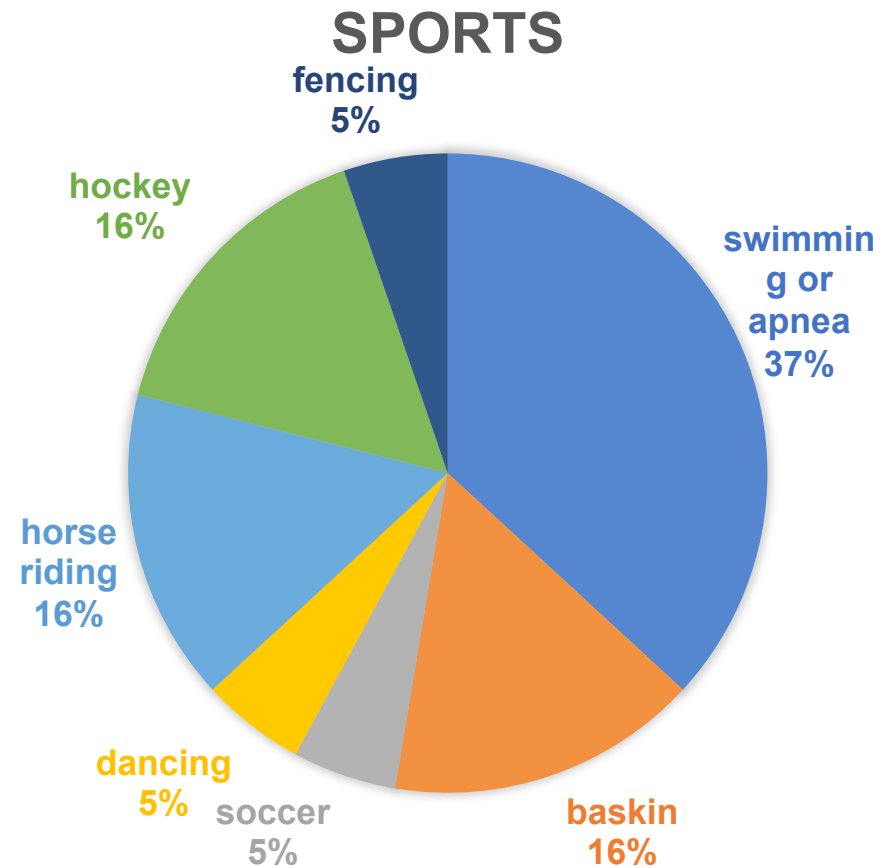


■ association ■ sports club ■ word-of-mouth



Results

- ✓ 3 children practiced **more than 1 sport**
- ✓ 82,3% mixed groups of **adults and children**
- ✓ 76,4% groups **exclusively for disable**
- ✓ 70,6% practice it as recreational sport with no competitions at least once per week
- ✓ Only 2 children received equipments form the health care sistem





Results: Child and Young Adult

perspective

Personal experience

- ✓ Sports for me is fun (82.3%)
- ✓ Sports made me feel that I can do things on my own (64,7%)
- ✓ Thanks to sport I have more friends (64.7%)
- ✓ I immediately found the team welcoming where I felt comfortable (58.8%)
- ✓ I don't mind to play sports with people without disabilities (35,3%)
- ✓ Sport interfere with school activities (11.8%)
- ✓ Doing sports I am more afraid of getting sick or hurt (5,9%)

Fear of not being able to play sports anymore

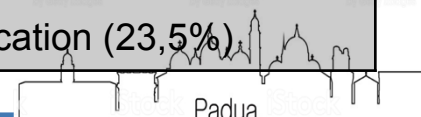
- ✓ NO (82-3%)
- ✓ YES (11.8%) : for fear of weighing too much; for fear that they will close disabled sports activities
- ✓ I don't think about it (5.9%)



Results: Caregivers perspective

<p>Sport impact on the caregiver</p>	<ul style="list-style-type: none"> ✓ I don't mind arranging my schedule around my son's practice (58,8%) ✓ My son's sport allows me to have more of a social life (52,9%)
<p>Sport activities on the child</p>	<ul style="list-style-type: none"> ✓ Sports stimulate my child's socialization (100%) ✓ Sport help my child to have and achieve goals (100%) ✓ Sports promote autonomy in my child (82,3%) ✓ Sport allows my son not to have disability perceived as a limitation (82,3%) ✓ Sports help boost my child's self-esteem (64,7%)

<p>Facilitators</p>	<ul style="list-style-type: none"> → Adequate structure(100%) → Adequate technical formation of providers (82.3%) → Adequate information (64.7%) → Adequate support from the health care system (17,6%)
<p>Barriers</p>	<ul style="list-style-type: none"> X Architectural (58,8%) X Cultural (52,9%) X Equipments (47%) X Economical (41,2%) X Logistic (23,5%) X Education (23,5%)





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What do the children and young adult like the most of practicing sport?

The best thing about playing sports is **being with others** (41.18%) and **feeling free** (41.18%).

«I have fun and go at high speed without being called back»

«teamgame

!»
«SOMERSAULTS IN THE WATER»

«Being able to move without ever falling»



How do parents feel when their child practice sport?

Parents **feel happy** (41.18%) and **proud** (41.18%) when they see their children playing sports.

«A PARENT EQUAL TO OTHERS WHO HAVE NORMAL CHILDREN»

«Lightened»

«Proud»

«Full of joy»

«Peacefu

l»





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«There are already physical limitations let's not put limitations in our heads as well ,**in life we must always try**, we can do everything in our way and if there is no way we can invent it»

«sport brings: 1. overall well-being of the body and mind, 2. emancipation 3. socialization, with an overall perception of a better quality of life»

«I would tell him to start a sports activity because **it changes your life**»

«I would tell this family that **anything is possible** and **limits are meant to be crossed**»

«even with disability, great goals can be achieved»

« **Do it!!** »

«try it, maybe you discover a passion and a **new way of considering yourself**»

«**sports integrate ,include ,bring happiness, enthusiasm and fun**»

«try it because it is a way to have fun together and clear your mind from **thoughts or problems**»

Both parents (52.94%) and kids (58.82%), encourage other kids with disabilities to try sports, the others empathized the beneficial effect of sport



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Conclusion

- ✓ Sport is associated with a positive experience of integration and fun for children.
 - ✓ Even for their families, sport represents a good experience despite the fact that it requires an important caregiver's commitment.
 - ✓ Sport is almost limited to children with physical disability
 - ✓ Data are still insufficient and further research are needed
- Caregivers and health care providers need to be aware of the importance of sports and support children in their desire to practice it.



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Sport in Pediatric Palliative Care: “Just do it!”

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***Thank you for your
attention***