



## VALIDATION STUDY

# Assessment of disabled paediatric patients for accessing palliative care: validation of a new tool

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## Findings:

*This article describes the validation process of the first Italian assessment tool for defining access criteria to Paediatric Palliative Care.*

## ABSTRACT

**BACKGROUND:** By reviewing the literature, no work has emerged about the presence of a Palliative Care Network dedicated to the Italian disabled pediatric population, however, there is an increase in the prevalence of children with ingrained illness and / or serious disabilities who are in need of such treatment. The difficulty in defining when a child becomes incurable persists. Along with the diagnosis of incurability, the other crucial factor is the extent of "care needs".

**AIM:** The aim of the study is to build an assessment tool for defining access criteria to Pediatric Palliative Care for patients with advanced illness and / or severe disability.

**METHODS:** An observational, prospective, multicenter study was conducted, by using the Clinical Assessment Tool (CAT) scale, which has been proposed by the paediatric hospice of Padua (Italy) without formal validation. We studied a non-randomized sample of 101 patients from five healthcare facilities in Northern Italy. We modified the CAT scale by adding items from other tools used in Palliative Care. The study was divided into two periods at a distance of one month, in order to assess the patients' clinical evolution.

**RESULTS:** Internal consistency of the CAT tool was good ( $\alpha=0.83$ ). Explorative factor analysis showed acceptable loadings on each item. Positive and negative predictive values were 0.97 and 0.98, respectively.

**CONCLUSIONS:** The scale is reliable in identifying individuals in need of Pediatric Palliative Care and seems a promising tool for assessing the needs for palliative care in children with ingrained illness and/or severe disability.

**KEYWORDS:** *Palliative care, pediatric, disability*

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STUDIO DI VALIDAZIONE

# La Valutazione dei pazienti pediatrici disabili per l'accesso alle cure palliative: validazione di un nuovo strumento

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## Riscontri:

*Questo articolo descrive il processo di validazione del primo strumento Italiano di valutazione per definire i criteri di accesso alle cure palliative pediatriche.*

## ABSTRACT

**INTRODUZIONE:** Esaminando la letteratura, non sono emersi lavori sulla presenza di una rete di cure palliative dedicata alla popolazione pediatrica disabile italiana, tuttavia, si registra un aumento della prevalenza di bambini con malattia radicata e/o grave disabilità che necessitano di tali cure. Persiste la difficoltà di definire quando un bambino diventi incurabile. Insieme alla diagnosi di incurabilità, l'altro fattore cruciale è l'entità dei "bisogni di cura".

**OBIETTIVI:** Lo scopo dello studio è quello di costruire uno strumento di valutazione per definire i criteri di accesso alle cure palliative pediatriche per i pazienti con malattia avanzata e/o grave disabilità.

**METODI:** E' stato condotto uno studio osservazionale, prospettico, multicentrico, utilizzando la scala Clinical Assessment Tool (CAT), che è stata proposta dall'hospice pediatrico di Padova (Italia) senza validazione formale. Abbiamo studiato un campione non randomizzato di 101 pazienti di cinque strutture sanitarie del nord Italia. Abbiamo modificato la scala CAT aggiungendo item di altri strumenti utilizzati nelle cure palliative. Lo studio è stato diviso in due periodi a distanza di un mese, al fine di valutare l'evoluzione clinica dei pazienti.

**RISULTATI:** La consistenza interna dello strumento CAT era buona ( $\alpha=0,83$ ). L'analisi fattoriale esplorativa ha mostrato carichi accettabili su ogni item. I valori predittivi positivi e negativi erano 0,97 e 0,98, rispettivamente.

**CONCLUSIONI:** La scala è affidabile nell'identificare i soggetti bisognosi di cure palliative pediatriche e sembra uno strumento promettente per valutare i bisogni di cure palliative nei bambini con malattia radicata e/o grave disabilità.

**KEYWORDS:** *cure palliative, pediatria, disabilità*

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## BACKGROUND

Patients suffering from life-limiting / life-shortening illnesses have developed during childhood a condition for which there is no therapy that can lead the person to healing. These patients show conditions of clinical deterioration and disability that last for many years, as premature death is potential but cannot be defined in time (1). Patients with "life-limiting / life-threatening" conditions often have cognitive disorders, communicative difficulties, nutritional problems, seizures and fatigue. The European Association of Palliative Care (EAPC) defines the disease of these patients as incurable, with complex needs and risk of death (2). There has been a marked increase in the prevalence of children with ingrown illness and / or severe disability: medical and technological progress has in fact reduced mortality, but at the same time has increased the survival of pediatric patients with serious and potentially lethal disease. A new type of patient with special, often integrated, multispecialistic and inter-institutional needs has arisen. Such needs are present during the whole lifespan, including childhood and adolescence. These children require Pediatric Palliative Care (PPC) (3–5). Even from a numerical point of view, the problem is not to be underestimated. It is estimated that there are more than 20 million children eligible for palliative pediatric care worldwide. The World Health Organization defines Palliative Care as "the active global care of the body, mind and spirit of the child, and includes active support to the family." The purpose of Palliative Care is, in fact, to obtain the highest possible quality of life for the patient and for his family (6). For some years, the idea that palliative care should be cross-sectional throughout the life of the patient has been accepted worldwide, definitively supplanting the idea that they should take place when there is no room for active treatments.

The definition of eligibility criteria of a newborn baby / child / adolescent for PPC is far from simple. Adopting the eligibility criteria for Adult Palliative Care in the pediatric area is not possible because children have very different and specific disease stories. The definition of Palliative Care Eligibility requires, in the pediatric field, the presence of an incurable disease as a primary criterion: but not all of the incurable pathologies require Pediatric Palliative Care, and the formulation of criteria that make a patient eligible is complex. In some categories an extreme difficulty persists in defining when a child becomes incurable. Therefore, in addition to the diagnosis of incurability, the other aspect that plays the decisive role in defining eligibility for PPC is the magnitude of the "problems" of the child and the family and hence the care needs (4). Three distinct levels can be identified, based on the priority of the patient's needs and his/her physical response to therapy and treatments:

1. First level of care - "palliative approach" in case of low-medium care intensity, requiring basic PPC interventions. Such interventions must be warranted by all health professionals;
2. Second level of care - "General PPC" in case of moderate / high intensity of care, requiring the intervention of those practitioners who are experienced in such disease, but also have specific training and competence in PPC. General PPC may also require support and supervision by a specialized team;
3. Third level of care - "Specialized PPC" in case of high care intensity: these situations require continuous intervention of professionals dedicated exclusively to pediatric palliative care, working in specific multiprofessional teams.

The need for palliative care in people with disabilities has only recently attracted the attention of researchers (7,8). Research in this field has not appeared until the beginning of this century. There is still a limited

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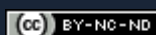


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empirical knowledge about the application of Palliative Care to people with intellectual disabilities (5,6,9–11). There is evidence that end-of-life care for people with disabilities is of lower quality if compared to the general population (7). It is also evident that people with intellectual disability are not sufficiently involved in making decisions about the end of their own life. Such decisions are sometimes based on their quality of life and compliance with treatment; In addition, potential life-saving treatments are offered less frequently to people with intellectual disabilities than patients who do not have such problems (8,9,12). The consequences are extremely severe and include a risk of premature death and impaired quality of life. Most palliative care services in Italy do not usually accept patients whose terminal condition is not due to neoplastic diseases. Terminally ill persons with intellectual disability are in fact an invisible population and often their specific needs are neglected, and are not seen as a priority or perceived as potential problems (12). Moreover, the use of subjective measures for assessing symptoms becomes problematic for these people who have cognitive problems and communication difficulties (9). However, it may be possible to adapt one of the many existing measures (scale) or to use an indicator to assess the quality of life, quality of palliative care and the care needs of these people (10,11). No literature has been found in this field so far. Nurses have the power to determine a positive change in their patients' life experiences, or to exert a negative influence. Quality of life thus becomes a central concept for all nurses (13). Service providers are increasingly responsible for the quality of services provided and the impact they have on people's lives. The quality of life context also offers a holistic approach that nurses should use. In fact nurses play an important role in identifying and meeting the health needs of the patient with intellectual disability (13). For these reason, we sought to validate a tool aimed at assessing the needs for palliative care in

persons with severe intellectual disability in the Italian setting.

## METHODS

### Study population

We enrolled a non-randomized sample of patients aged 2 to 25 years, suffering from ingrained illnesses ascertained by medical diagnosis, and responding to the general worsening indices and “green lights” at the beginning of the study.

### Research approvals

We complied with the rules of the local ethical committee; approval was obtained from the managers of all the hospitals involved. The caregivers or legal representatives of all patients gave their informed consent, accordingly to the Italian law in force. The principles contained in the declaration of Helsinki and in the Italian law on data protection were applied.

### Design

This was an observational, prospective, multicentre study, conducted in five hospitals in Northern Italy (Ospedale Sant’Anna di Como, La Nostra Famiglia di Bosisio Parini, Casa di Gabri di Rodero, Ospedale dei Bambini Vittore Buzzi di Milano, Centro Clinico NEMO) dedicated to paediatric disabled patients.

### Measures

The tool used in the study is based on the Clinical Assessment Tool, which is a scale designed by the Department of Health, Social Services and Public Safety of Northern Ireland. The assessment scale is targeted at children and young adults with chronic, long-term conditions. The instrument can describe the child's conditions. The beginning of the scale is characterized by the inclusion of the "General Worsening Indicators" taken from the project "Teseo-Arianna" (Age.Na.s – Italian National Agency for Regional Health Services) and the "Green Lights" for considering a child eligible for Pediatric Palliative Care (14). Therefore, the elements of

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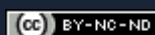
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deterioration (for example: reduction of autonomy, impaired self-care, intolerance to physical activity, etc.) are included in the scale. The tool is divided into 11 evaluation areas: Breathing, Food intake, Seizures or altered states of consciousness, Vitality of skin and tissues, Mobility, Continence and elimination, Medications, Communication, Sleep and rest, Pain, and Specific / unexpected events.

Each area evaluates the presence or absence of a number of life-threatening clinical conditions, which receive a rating from 0 to 25 depending on the category. Based on the score, the patient needs the first level of care – palliative approach (score  $\leq 29$ ), second level of care – general PPC (score 30 – 49) or third level of care – Specialized PPC (score  $> 50$ ).

In addition to the original scale, we chose to introduce the assessment of "vomiting and diarrhea" (taken from the EORTC QLQ-C30 scale) in the Food Intake category; NPUAP staging was added to the "Vitality of skin and tissues" domain. Finally, the Revised Flacc scale was added to the "Pain" rating. These characteristics were not added as individual items, but were introduced in already existing parts of the scale, to allow more precise assessment of the patient. For this reason, the scoring criteria remained the same as in the original CAT. We chose to call the final tool "the Modified-CAT" to distinguish it from the original scale.

Because of the need for preparing an Italian version of this modified CAT, we adopted the back-translation method. The modified CAT was translated from English into Italian by two independent translators (nurses with certified knowledge of English and experience in validation studies) and then back-translated into English by a teacher of English. The Revised FLACC is a separate scale; we chose to add the Italian version, validated and published by Di Bari et al. (15). The final list of items of the modified

CAT is shown in tables 1 and 2, in English and Italian respectively.

Modified CLINICAL ASSESSMENT TOOL				
Care needs	Write in score and date			
Breathing				
Food intake				
Seizures or altered state of consciousness				
Skin and tissue viability				
Mobility				
Continence and elimination				
Medication				
Communication				
Sleep and rest				
Pain				
Specific sudden/unpredictable events				
<b>TOTAL</b>				

Table 1 - Modified Clinical Assessment Tool (English)

Modified CLINICAL ASSESSMENT TOOL				
Bisogni Assistenziali	Dati di rilevazione e punteggio			
Respirazione				
Apporto nutrizionale				
Crisi epilettiche o stati alterati di coscienza				
Vitalità della cute e dei tessuti				
Mobilità				
Continenza ed eliminazione				
Farmaci				
Comunicazione				
Sonno e riposo				
Dolore				
Specifico evento improvviso/imprevedibile				
<b>TOTAL</b>				

Table 2 - Modified Clinical Assessment Tool (Italian)

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## Data analysis

Internal consistency was assessed by calculation of Cronbach's alpha coefficient. Exploratory factor analysis was conducted after Bartlett's test of sphericity and Kaiser-Meyer-Olkin's measure of sample adequacy. The positive and negative predictive values of the scale were calculated by comparing the scores provided by the modified scale with objective worsening or improvement of clinical condition as documented in the medical records of our patients. Analysis was conducted with SAS® University Edition for MacOS.

## RESULTS

Between January 3 and February 27, 2017, 101 patients were enrolled, 68 males (67%) and 33 females (33%). The study was predominantly centered on the pediatric patient, but also took into consideration young adults (18-25 years). 94 patients were under the age of 18, and 7 were aged 18 to 25.

In 23 patients, disability was acquired through cerebrospinal lesions or traumas such as drowning, stroke, cardio-circulatory arrest and severe head injury. In the remaining 78, disability was due to congenital disorders caused, for example, by chromosomal deletions or malformative/degenerative syndromes. In one case the disease was caused by the mother (fetal-alcohol syndrome).

The most commonly occurring diseases in the sample were: Cornelia de Lange (11.88%), Double Infantile Cerebral Paralysis (12.87%), Spinal Muscular Atrophy II (6.93%) and Tetanus Spastic Dystonia (6.93%). The other diseases included various forms of microcefalia, Down syndrome, and cromosomal deletion problems.

Data collection was carried out in two separate moments (T0 baseline and T1 after one month) performed by administering the modified-CAT. At

baseline, 69 patients (68.31%) had a score  $\leq 29$  (still 69 at T1), 19 (18.81%) scored 30 to 49 (were 21 at T1, 20.79%), and 13 (12.87%) scored 50 or more (11 at T1, 10.89%).

Over the span of one month, 7 patients improved their scores and 2 worsened. The positive and negative predictive values were 0.97 and 0.98 respectively. Only two patients (one who improved the score from 41 to 14 points and the other who worsened it from 29 to 53) shifted to another category due to changes in their scores.

The most compromised needs in the sample were breathing (37.6% of the total), food intake (76.23%), mobility (81.18 %), continence (80.19%), medication (93.06%) and communication (69.30%). Moreover, during data collection it was found that 13 children who had a score  $\geq 50$  points at baseline, 7 of them at T1, had a higher number of scheduled follow-up consultations to the rest of the sample. In fact, patients who show a high total score have a high score in almost all domains investigated by the scale, which means that they have generalized clinical deterioration and are therefore followed by more specialists within the multidisciplinary team.

As regards the validation of the new scale, the rotated factor pattern explained 67% of the variance with acceptable factor loadings (Table 3), which suggests that all items contribute to describe the situation of these patients, without being redundant. The only exception was the "Specific sudden/unpredictable events" item, which loading was negative, indicating lack of correlation between this item and the others. This finding can be explained by considering the nature of such events, which cannot be foreseen and do not occur according to a specific pattern. Nonetheless, this item appears necessary from a clinical point of view.

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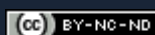
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Item	Factor 1
Breathing	0.33
Food intake	0.81
Seizures or altered state of consciousness	0.48
Skin and tissue viability	0.3
Mobility	0.63
Continence and elimination	0.81
Medication	0.89
Communication	0.69
Sleep and rest	0.45
Pain	0.62
Specific sudden/unpredictable events	-0.09

*Table 3 – Factor loadings of the items*

## DISCUSSION

The initial problem was the difficulty in establishing the need to initiate Paediatric Palliative Care for severely disabled people, and on the other hand, the total absence of useful tools for the purpose in the literature. The only available tool had never been fully validated.

Our Modified-CAT has shown good internal consistency. Factor analysis has shown that all items have a role in depicting the clinical situation of the patient. In addition, positive and negative predictive values (0.97 and 0.98 respectively) indicate that the scale has a good ability to discriminate patients who need palliative care from those who do not need it. The Clinical Assessment Tool is able to investigate the level of compromised needs, which influences the level of cure response needed for the child with incurable pathology.

Children with high scores (50 points or more) were hardly ever assisted at home. In addition, data collection at T1 showed that patients who showed a high score at baseline had more access to scheduled follow-up visits than the rest of the sample. Indeed, these patients present a generalized clinical worsening in almost all scale domains (eg, PEG, tracheostomy, with inability to walk and double incontinence).

These results demonstrate that the Clinical Assessment Tool scale is a valid and reliable tool that can certainly be of help in clinical practice. In support of this hypothesis, from the analysis of the collected data, there were no significant differences between the application at baseline and T1. Administering the scale requires 15 minutes: 10 for reviewing the clinical record and 5 for completing the assessment.

Notwithstanding the length of the tool, it appears easy to understand and leaves no room for personal interpretation. The instrument is presented in that format because the ultimate goal is to investigate the most compromised care needs in patients who have communication difficulties and therefore cannot express their own compromised needs independently. The tool gives a general picture of all the possible complications that the patient can present. In addition, the patient's anthropometric recordings are not provided for the scale compilation, so vital parameters are not needed, but direct observation and review of the clinical record is sufficient.

## Limitations

A limitation of the study was the lack of involvement of the caregiver / family in the assessment. The latter could provide useful information on the applicability and ease of use of the instrument at home, including those outside clinical practice, but close to children who present such problems. In addition, there was a partial difficulty in finding and contacting structures that featured a study population responding to the inclusion criteria.

In addition to the diagnosis of incurability, the other important parameter for eligibility to CPP is the magnitude of the "problems" of the child and the family (clinical, psychological, organizational, spiritual, ethical), i.e. the needs of care by these triggered. Currently, in the worldwide scientific literature, there are no valid and specific tools for assessing care needs

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and hence compromised care needs in disability patients, although several studies have demonstrated the need to initiate a Palliative Care pathway for these patients, especially in specific case of pediatric patients. The Modified CAT can be used in clinical practice to evaluate compromised needs in this category of patients. It has proven to be a reliable tool in the pediatric population / young adult population and could be extended to the adult population in order to create a unified assessment scale applicable to all those with disabilities. The scale is also an excellent tool for tracing the patient's clinical / therapeutic outlook for long periods of time, thus detecting those patients who, over the months, have a worsening or improvement in their Clinical condition. Future studies should pay attention to the caregiver's/family's assessment of the applicability and ease of use of the instrument at home.

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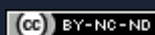
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