

# Psycho-educational play supports occupational activity in ALL children during hospitalization. Effects on children's fine motor skills, HRQOL, parents' perception of the child

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**ABSTRACT:** *This study aims at exploring the positive effects induced in children with acute lymphoblastic leukemia (ALL), in their parents and in the quality of life perceptions by the introduction of a kit of psycho-educational play activities (MoFis-I) designed to stimulate children's fine motor skills and to minimize occupational deprivation associated with long hospitalization. Moreover, this pilot research intended to evaluate the feasibility of the MoFis-I in a health-care setting, measuring if it is perceived as pleasurable and stimulating and evaluating its benefits for cancer children and their families. Results indicated that on average children increase their motor functioning in manual dexterity after participation in stimulation activities. Parents' interviews with the COPM reveal that after the kit play activities children show a slight improvement in overall occupational performance related to an increase in the area of productivity and self-care. The MoFis-I has been judged as transportable, easy to build up, pleasant and stimulating tool to be used for enhancing children's occupational activity.*

**Keywords:** *psycho-educational play, fine motor skills, health related quality of life (HRQOL)*

## I. INTRODUCTION

The diagnosis and treatment of a malignant tumor in children represents a very stressful event for children and their families (Hicks & Lavender, 2001). Despite the evolution of treatments and the increase in the survival's chances, children with cancer or childhood cancer survivors present numerous medical side effects and long-term outcomes that compromise their well-being and quality of life (Langeveld, Grootenhuis, Voûte, de Haan, & van den Bos, 2004). With increasing life expectancy, the experts have tried to describe and understand how the disease experience affects the future outcomes of these children in order to intervene, where possible, to facilitate the developmental trajectories of cancer survivors becoming similar to those of healthy peers. Physical and psychological suffering is not caused only by illness but also by long months of hospitalization and therapies, with consequences that can occur both in the short and long term. Invasive therapies such as chemo or radiotherapy

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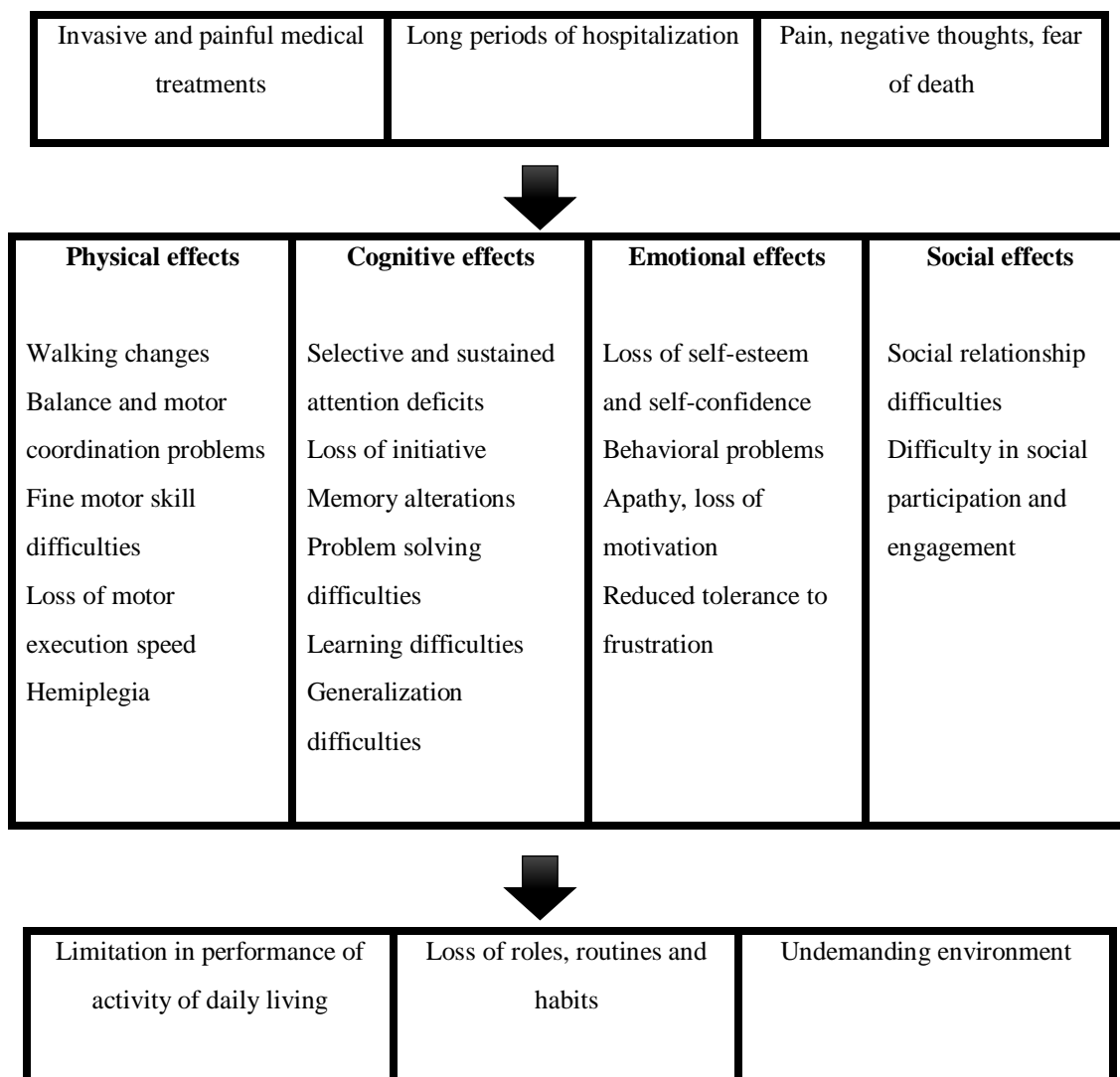
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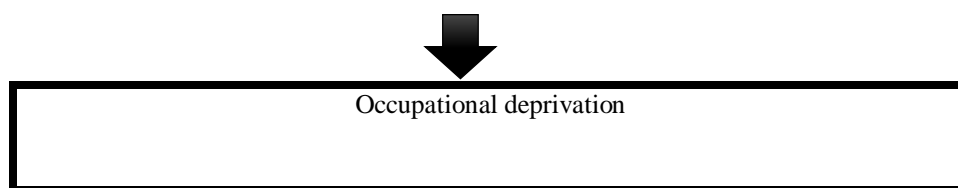
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play a fundamental role in child survivorship and, however, can cause numerous side effects. These vary from patient to patient depending, for example, on general health conditions, tumor site and type of treatment (AIRC, 2013). Among the short-term sequelae we find fatigue, nausea and vomiting, ulcers in the mucous membrane of the digestive system and mouth, taste alteration, loss of appetite, diarrhea, constipation, infections, anemia, bleeding, hair loss, hair loss, of eyelashes and eyebrows (Söntgerath & Eckert, 2015; Lofstad, Reinfjell, Hestad, & Diseth, 2009; Götte, Kesting, Winter, Rosenbaum, & Boos, 2015). Furthermore, during the treatment phases, changes in the motor balance in strength and balance can occur in the child (Bernabeu et al., 2009). The long-term sequelae are instead identifiable in a series of physical and psychosocial disorders that depend on numerous factors: the diagnosed disease, drugs, type of treatment (Pinquart & Teubert, 2012; Scheede-Bergdahl & Jagoe, 2013), age, tumor's location, lack of stimulation, long months of hospitalization and reduced / absent interactions with friends and peers (Taverna, Tremolada, Bonichini, Basso, & Pillon, 2016; Tremolada, Taverna, & Bonichini, 2019; Bernabeu et al., 2009). Long-term effects can involve the child's physical, cognitive and social developmental domain and determine motor difficulties (global and fine), attentional or executive functioning, communication, academic learning and socialization with important consequences on the future quality of life of the child.





**Figure 1** The consequences of the oncological disease on children occupation and well-being (adaptated from Bernabeu et al., 2009)

### *Playing in hospital*

Several scientific studies have focused on the positive effects induced by the introduction of playing activities in the hospital similar to those to which children would have access outside the medical context. "Normalizing" the hospital aims at giving children the opportunity to perceive the medical setting as more familiar, to keep a connection with the world, and to better cope with the illness. Inpatients and their families are offered activities like cineforums, school-based exercises, and intervention programs such as pet, musical or clown therapy to name a few. Facilities like playrooms are provided to spend some time with peers during extended hospitalization periods and to meet friends in a pleasant and stimulating environment. In general, playing means for children active experimentation that promotes learning skills, abilities to express emotions, and the opportunity to put into practice acquired skills for building competence. For this reason, parents are encouraged to support child's wherever and at any time it is possible. Any spontaneous activity that the child performs with pleasure can be defined as a play. Regardless of culture and origin, children, if their health conditions allow it, find the time to play (Rollins, Bolig, & Mahan, 2005). Because of the extraordinary importance of play in children's lives, many specialists have decided to use play as a vehicle for information and communication. Playing serves as an intervention tool to allow the expression of negative emotions caused by the hospitalization's experience, promotes the psychosocial well-being of young inpatients helping them to cope with the illness, and finally normalizes the medical setting allowing to meet children' developmental needs and to provide experiences similar to those experienced by peers outside the hospital.

The medical play, for example, is a common technique used by health personnel to give children the opportunity to get in touch with hospital devices (needles, syringes, catheters, gauzes, plasters, thermometers, stethoscopes, etc.) in order to reduce anxiety and to cope with medical visits, therapeutic procedures and hospitalization periods. The familiarization with medical and hospital equipment also offers children the advantage to express and process their feeling, to face false beliefs, to distinguish reality from fantasy and to better cope illness experience increasing their understanding (Beickert & Mora, 2017; Webb, 1995). Positive effects related to the medical play are variously documented and include the stress' relieve in dealing with surgical interventions (Silva, Austregésilo, Ithamar, & Lima, 2017), anxiety reduction (Potasz, Varela, Carvalho, Prado, & Prado, 2013; Bloch & Toker, 2008; Ellerton, Caty, & Ritchie, 1985), foster control over negative emotions related to one's own hospitalization or that of a family member (Nabors & Kichler, 2015).

The therapeutic play, unlike the medical play, represents a structured activity aimed at promoting psychosocial wellbeing (Li, 2012), coping skills and ensuring the expression of the emotions of hospitalized children. The therapeutic play includes various types of activities, including expressive arts and crafts, pretended play with dolls

and puppet shows. Each therapeutic play can be planned in such a way as to ensure that interaction with health care staff is aimed at helping children express, and to process their emotions. The benefits deriving from the therapeutic play concern the management of emotions (William Li, Lopez, & Lee, 2007), the understanding of thoughts and concerns projected in the play or in the artistic products created (drawings, masks to cover the face during therapeutic procedures) (Schwartz & Albino, 1983), and better adaptation to hospitalization (William Li, Lopez, & Lee, 2007).

The play in health care settings is used as an opportunity for normalization to face extended periods of hospitalization and to promote typical development for severely ill children. These activities include video games, puzzles, reading books, as well as table games. Thus, the hospital becomes a little less aseptic, closer to the developmental needs that children have despite their health conditions (Haiat, Bar-Mor, & Shochat, 2003). A more "normal" context of care, with spaces dedicated to entertainment and playing activities similar to those that the child would have access outside the hospital, allow a less alienating hospitalization experience and to maintain a bond with healthy life by spending a funny time doing enjoyable activities with peers.

Prior review study on different forms of play in hospital (Burns-Nader & Hernandez-Reif, 2016) point out a lack of literature of research studies on psycho-educational play in health care settings aimed at occupational rehabilitation or intervention in developmental domains compromised by long periods of hospitalization or by therapeutic treatment. In fact, play can be used as a tool to promote the acquisition of necessary skills for later key competences and child's future educational goals by means of fun activities. Moreover, psycho-educational play aims at stimulating cognitive abilities, enhancing learning processes and instrumental functions while expressing and sustaining one's own proficiency. For this reason, the link with normal world outside the hospital is not maintained only through the recreation of settings and opportunities resembling those experienced in the life without illness, but keeping alive the hope of existence in good health beyond illness. Thinking about the child's future means at succeeding at creating the conditions for his active participation in that social, educational, emotional life awaiting him once he is healed.

### ***Hospitalization and the risk of occupational deprivation***

Some studies have shown that a limitation in the production and in carrying out one's own abilities, whether temporary or lasting for extended time periods, as well as the loss of an important function can lead to a state of occupational deprivation with negative consequences on later child development (Rodger & Ziviani, 2006; Segal, 2004). The risks associated with an impediment to achieve or even purely participating in those activities that form an integral part of a normal development path (occupational deprivation), include low self-esteem, difficulties in social adaptation, and health problems of various kinds. Being hindered to take part to daily life activities, a suddenly interruption of habits and familiar routines (for example, stopping eating alone, buttoning, writing or playing) can lead children to believe that they are incapable and incompetent, influencing negatively the perception they have of themselves, the confidence to be at the same level as their peers. Furthermore, the diagnosis and treatment of a tumor in pediatric age, as well as abruptly interrupting the personal habits and autonomies of the child (Rebeiro & Cook, 1999), can further involve psychosocial effects such as marginalization and isolation from the peer group (Segal, 2004; Moruno Miralles, Ramón, & Valero, 2016). The condition of quarantine and the hygiene requirements related to hospital care restrict interactions to adults only, including health staff and

specialists, close family members, impacting and limiting severely the child's participation and socialization (Bernabeu et al., 2009).

During hospitalization the entire family nucleus is forced to adapt to the needs and times of the health facility. The new situation causes insecurities in parents with respect to their role, sometimes they feel guilty for the situation, incompetent and incapable, caught in a grip of impotence for the severe illness of their children (Mancaniello, 2006). Feelings and emotions like the ones just described risk to modify the expectations that parents may have regarding the development and autonomy of their children, pushing them to exhibit a protective care by replacing them in performing actions that they could carry out alone instead of promoting and supporting daily life skills.

### ***Preschool leukemia and limitations in the development of fine motor skills***

Preschool children with Acute Lymphoblastic Leukemia (ALL) may experience significant changes in the development of motor skills. Neuropathies at the level of the peripheral nervous system induced by the use of treatment drugs, such as vincristine, may be the cause of weakness in the distal musculature (Vainionpää, 1993; Vainionpää, Kovala, Tolonen, & Lanning, 1995) reduced muscular power in the upper and lower extremities (Gomber, Dewan, & Chhonker, 2010; Hartman, van den Bos, Stijnen, & Pieters, 2006), motor clumsiness, of poor coordination in particular manual and bimanual (Harila-Saari, Huuskonen, Tolonen, Vainionpää, & Lanning, 2001; Hockenberry et al., 2007), paresthesia of the fingers of hands and feet, loss of sensitivity to stimuli or altered perception of pain, temperature and proprioception, and finally loss of tendon reflexes (Lehtinen et al., 2002). These difficulties are reported both in the acute phase of medical treatments, and in some cases in the less intensive phases persisting up to two years after the end of the management and care of the cancer disease (Ramchandren et al., 2009; Reinders-Messelink et al., 2001; Taverna et al., 2016; Reinders-Messelink et al., 2001; Tremolada, Sbalchiero, Bonichini, Pillon, & Carli, 2011).

In typically developing children, fine motor skills have been associated with mathematic and reading achievement (Polatajko & Mandich, 2004; Cameron, Cottone, Murrah, & Grissmer, 2016; Grissmer, Grimm, Aiyer, Murrah, & Steele, 2010; Kaemingk, Carey, Moore, Herzer, & Hutter, 2004; Pitchford, Papini, Outhwaite, & Gulliford, 2016). Also the results coming from neuroimaging studies confirm the idea that there is a relationship between the first mental calculation skills and the movement of the fingers (Andres, Seron, & Olivier, 2007; Zago et al., 2001) since being able to count with hands reduces the working memory workload allowing a higher availability of cognitive resources for learning new contents or strategies in solving problems (Alibali & DiRusso, 1999). Conversely, it could also be assumed that a poor digital dexterity could correlate with a reduced performance in problem solving or counting accuracy (Barnes & Raghobar, 2014). A possible explanation of the mechanisms underlying the relationship between fine motor skills and academic performance is that finger and hand movements consent children to create a visual correspondence one-to-one, to group objects on category basis (number, shape, size) and to develop a procedural competence at counting. Finally, digital dexterity helps children to achieve a good level of automaticity in grapho-motor skills, ensuring them the opportunity to pay more attention to the grapheme-phoneme relationship, to decode properly during reading, and to master mathematical concepts (Becker, Miao, Duncan, & McClelland, 2014).

Considering the fact that the peak incidence of leukemia in infancy occurs when children are between 1 and 4 year-olds (Howlader N, Noone AM, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds.), 2019), the effects of reduced motor function may have long-term consequences in learning the first mathematical concepts, in the letter-sound connection, and in the emergent literacy. More studies are required on leukemic children, a population at risk of numerous developmental neurocognitive deficits, to understand the relative contribution of motor skills and visual-motor integration abilities on the acquisition of foundational academic competences (Kaemingk et al., 2004).

Some authors have pointed out that fine motor skills difficulties are sensitive to rehabilitation (Dankert, Davies, & Gavin, 2003) and can therefore be addressed with targeted psycho-educational activities.

This exploratory research aimed at observing the effects produced by psycho-educational playing activities to enhance digital dexterity and grapho-motor skills in preschool aged children hospitalized for leukemia. Moreover, the present study was designed to understand the psychological consequences of parents' involvement in children fine motor skills stimulation to maintain positive expectations about future life looking beyond the tumor disease.

### **Research questions**

The primary objective of the present study was to evaluate how parents, leukemia children and health care staff appraise a kit of psycho-educational stimulation activities designed to enhance fine motor skills of hospitalized pediatric patients. Moreover, the study aims at describing the feasibility of the kit in a hospital setting, measuring if it perceived as pleasurable and stimulating, and evaluating its benefits for cancer children and their families. Finally, the study analyzes possible associations between child's socio-demographic characteristics, quality of life perception, and fine motor skills performances.

## **II. MATERIALS AND METHODS**

In this study, 13 children (7 males and 6 female) participated, with an average age of 58.31 months (SD = 9.09; range: 44-70). Participants were treated at the Pediatric Haematology-Oncology Clinic of the Padua Hospital for acute lymphoblastic leukemia (ALL). 23.1% were hospitalized (n=3) and 63.9.0% (n=10) came periodically to the Day Hospital for routine visits. Former children (30.8%) were in the consolidation phase of therapy, while the latter were in the maintenance phase (69.2%).

All parents understood and spoke the Italian language and were Caucasians except a family that was Moldovan. Socio-demographic information of the pediatric patients obtained through the medical records and during the COPM interview are reported in Table 1.

**Table 1** Sociodemographic information of the participants to the present study

	<b>Mean</b>	<b>SD</b>
Age in months (range 44-70)	58.30	9.09
	<b>Frequency</b>	<b>Percentage</b>

Assessment time	Acute period=4	30.8
	Maintenance period=9	69.2
Age groups	44-53 months=6	46.2
	62-70 months=7	53.8
Gender	6 females	46.2
	7 males	53.8
Leukemia Risk band	HR=7	53.8
	SR=6	46.2

### ***Instruments***

Data were collected using two standardized tools: the Movement Assessment Battery for Children-second Edition (M-ABC-2) (Henderson, Sugden, & Barnett, A.L., 2007) and the Canadian Measure of Occupational Performance (COPM) (M. C. Law et al., 2014). Two ad hoc questionnaires concerning satisfaction and feasibility of the Kit (Kit MoFis-I) in hospital setting were created and filled in by healthcare professionals and cancer children. Furthermore, children's perceived quality of life was assessed through the administration to the parents of the PedsQL (Varni, Seid, & Rode, 1999).

### ***Movement Assessment Battery for Children-second Edition (M-ABC-2)***

The Movement Assessment Battery for Children-second Edition (M-ABC-2) is a standardized tool used to test fine and gross motor skills with the purpose to identify individuals with motor function impairments. Children are required to perform 8 tasks grouped into three sections (Manual Dexterity, Aiming and Grasping, Balance) on which they are scored and rated. The performance test MABC-2 covers three age bands: 3:00-4:11 years, 5:00-10:11 years and 11:00-16:11. The present study involved the administration of the Manual Dexterity scale only, which include the following three tasks: inserting coins into a piggy bank, threading beads into a wire and tracing a path inside margins with a pen. The M-ABC-2 provides a total score and a standardized score adjusted for age and percentile of the motor functioning of the assessed individual. The MABC-2 battery provides a "traffic light" system that allows to interpret performance scores according to a risk categorization. Any child whose score falls at or below the 5th percentile is regarded as having a significant movement difficulty (red zone), between the 6th and 15th percentile at risk of developing motor difficulties that require to be monitored over time (amber zone), and above the 16th percentile as unlikely to have a movement difficulty (green zone).

The M-ABC-2 test requires an individual setting. The ideal assessing room should be 6m x 4m in size and have at least one smooth white wall (preferably without windows). Furthermore, it should be well lit and ventilated. There must be a table and two chairs available. Recommendation are provided that table and chairs height are adjusted according to the height of the child to be evaluated. The table surface should be approximately at the level of the child's elbow when seated. Finally, the child must be able to rest his feet firmly on the ground or on a raised platform.

### ***Pediatric Quality of Life Inventory (PedsQL 3.0-Parent Version)***

It is a paper-pencil questionnaire (Varni et al., 1999) to assess the perceived quality of life in children with cancer. Existing versions are filled in by parents of children aged 2-4 years (Toddler Module) and 5-7 years (Young Child Module). The instrument consists of 27 items grouped in different scales measuring four dimensions of health related quality of life (HRQOL): physical (pain, nausea), emotional (treatment anxiety, procedural anxiety, worry), cognitive problems (paying attention, remembering, concentration) and social (perceived physical appearance, communication). The PedsQL consists of questions designed to measure the extent of a problem in the last week using a 5-point Likert type scale (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem).

### ***Canadian Occupational Performance Measure (COPM)***

COPM is an individualized outcome measure designed to capture the change in occupational performance. It is administered as a semi-structured interview that allows respondents to identify problematic areas of occupational performance related to daily life activities of self-care, productivity and leisure. The COPM is mainly used to identify in which areas of occupational life the individual needs to set change objectives and formulate a targeted intervention program with rehabilitation staff able to highlight any deviations from the initial assessment. The COPM is designed to target client-perceived problem skills in daily function asking the respondent to assign a score in the self-care, productivity and leisure domains taking into account both the perceived importance of the occupational performance areas as well as the client's satisfaction with present performance. The interviewee is asked to prioritize and choose up to five occupational problems by rating the importance of knowing how to perform each of the indicated activities, and how much he perceives these issues as impacting or restricting his everyday life using a scale from 1 to 10 (1=not at all important; 10=very important). In a second step, the 5 most important activities are assigned a performance score (1=they are not able to do it; 10=perfect performance) and one of satisfaction (1=not at all satisfied; 10=completely satisfied). Overall performance and satisfaction scores are calculated by dividing the sum of the scores by the number of problems. Any variances in performance and satisfaction can be detected by a second administration of the COPM after a pre-established period of intervention based on agreed goals. This post intervention assessment enables the individual and the rehabilitation staff to have a concrete image of changes which have occurred during the therapy process, to monitor the implementation of occupational performance, and to adapt the treatment objectives. A shift of two or more points in the performance mean value is considered clinically significant (M. Law et al., 1990; Baptiste et al., 1993). The COPM has been validated in many populations, including the Italian one (Spadaro et al., 2010). COPM can be administered to adults and children from 8 years of age (M. C. Law et al., 2014). In this study the COPM was compiled by parents as first caregivers, reliable and "expert" informants of their child's needs, abilities, difficulties and personality, as described in some previous work (Cusick, McIntyre, Novak, Lannin, & Lowe, 2006).

### ***Kit MoFis-I fun questionnaire***

Children were asked to rate the Kit activities on a 5-level Likert items in the following dimensions: playfulness, attractiveness, degree of interest, pleasure and satisfaction in the execution. The questionnaire consisted of 9 items, 5 with a closed and 3 with an open format.



### ***MoFis-I Questionnaire***

This questionnaire was designed to measure the feasibility of the Kit MoFis-I in health care settings. It consists in 13 questions to be answered by an adult for collecting information on the intrinsic characteristics of this set of implements to be assembled and worked up: low-priced, material easily available, transportable, clear instructions, pleasant, progression from simple to complex, presence of variants with different degrees of difficulty. Health professionals such as psychologists, trainees and volunteers were asked to fill in the questionnaire answering each item on a 5-point Likert scale (1=totally disagree; 5=completely agree). The items concerned the feasibility of the kit, the perceived problems, the amount of time involved for psycho-educational play activities and the pleasure using it. For example: The stimulation Kit seemed to me difficult to use; It was difficult to find the material to build up by the Kit; The child showed to be bored in doing the activities of the kit; I wouldn't want to use the kit other times.

### ***Place and data collection***

Children took part to the present study after completion of parents' informed consent for data collection and processing, for video recording and/or child's hands photo shooting while carrying out a psycho-educational activity.

The MABC-2 and the COPM were administered in two distinct settings. Hospitalized children in the pediatric cancer ward were subjected to continuous infusion of chemotherapy and cortisone drugs by central venous catheter (CVC), had great fatigue and difficulty in maintaining the sitting position. For these children research instruments were administered while sitting or lying in bed. Children hosted in the Day Hospital performed the three Manual Dexterity tests of the MABC-2 in the play or in the school area. These children were seated during test's administration but table and chairs size were not adequate for their height.

### ***Research design and data analysis***

In this study, a descriptive research design was used, assessing both the fine motor skills of hospitalized children and of the young patients of Day Hospital (T1). The intervention with Kit MoFis-I on children's fine motor skills was provided only to some patients and exclusively on these children the manual dexterity competence was retested (T2). The average distance between the pre- and post MABC-2 tasks administration was 12.6 days.

At the end of the psycho-educational intervention program (T2) children completed the Kit satisfaction questionnaire. Parents were interviewed with the COPM twice, pre- and post-intervention. Of the 5 parents who had initially joined the psycho-educational program, one did not carry out the semi-structured COPM interview at T2 because the son had contracted a virus that required him to be admitted to the isolation regime. Consequently, only 3 mothers and 1 father returned information on the children's occupational performance.

### ***The Kit MoFis-I***

Stimulation of fine motor skills in hospitalized children took place using the Kit MoFis-I, an intervention program designed to improve the fine and grapho-motor skills of children aged between 4 and 6 years through 15 specific activities. The psycho-educational play activities of the Kit have been studied in order to achieve 3 objectives: a) to improve the functions of the hand, in particular manual dexterity, digital dexterity, in-hand

manipulation and visual-motor coordination, considered essential to the performance and to the participation in daily life activities and foundational for the development of grapho-motor competence; b) to develop manipulation skills related to autonomy and learning activities; c) to increase manipulation strength and endurance during fine motor activities.

The 15 activities can be carried out with a set of tools and implements that are inexpensive, easy-to-find (staples, elastic bands, plasticine, plastic bottles, pencils etc.), and transportable. Instruction for assembling the related material are given in detail to facilitate the administration both by occupational therapists or by other health personnel like for example psychologists, nurses, educators, hospital school teachers, volunteers and parents. All psycho-educational play activities can last even just a few minutes, are presented in order of progressive difficulty, are attractive and funny. At each stimulation session with the Kit, the child must carry out 3 different activities, each of which trains different fine motor skills: activities for manual dexterity, activities for digital dexterity and activities for visual-motor coordination.

The duration of the daily stimulation depended on the health and fatigue conditions of children. For children hospitalized in the cancer ward the administration took place on daily basis and mostly in bed. The duration of the intervention was of maximum 10 minutes because after this time the children resistance diminished significantly. It was not always possible to administer the three activities during the same session.

For the children of the Day Hospital, the administration was scheduled once/twice a week, based on the medical examinations the child had planned. For the children of the Day Hospital, the Kit was performed in the area dedicated to the school, although the activities often had to be interrupted by doctors and nurses when children had to undergo routine medical visits. For these children the intervention program had a variable duration, from 10 to 50 minutes.

In the present study the psycho-educational play activities were conducted mainly under the supervision of an occupational therapist and two psychologists present in DH and in the ward.

### III. RESULTS

To answer the research questions of the present study data collected were analyzed to describe the quality of life perception of leukemia children and their actual development in the manual dexterity domain (1), possible association between child's characteristics, fine motor skills and quality of life (2), and finally the feasibility of the kit in a hospital setting looking at parents, children and health care staff perception of its benefits and critical aspects (3).

#### *1. The perceived quality of life and fine motor skills in children with leukemia*

In Table 2 are presented data concerning the perceived quality of life in children with leukemia.

**Table 2** Means, standard deviations and score ranges of the PedsQL in children with cancer (T1)

	Mean	SD	Range
PedsQL Total	72.97	14.88	56.48-97

PesQL Physical	69.13	16.37	50-96.88
PedsQL Emotional	77.67	18.34	53.13-100
PedsQL School	74.96	13.95	60-100
PedsQL Social	69.34	21.40	37.50-100

The lowest scores are perceived in the physical and social domains as reported in Table 2, even if the standard deviations indicate a wide individual variability. Fine motor skills of cancer children are reported in Table 3 with mean standard values and range scores. Standard scaled scores of manual dexterity scale have been then converted in percentiles showing that 8 children were below the 50th percentile, while the remaining 5 are at the 50th percentile or even higher.

**Table 3** Manual Dexterity standard scores of cancer children at the MABC-2 (T1)

	Mean	SD	Range
MD1 preferred hand	8.58	4.27	1-15
DM1 other hand	7.69	3.19	1-13
DM2	9.31	3.27	4-14
DM3	8.46	3.12	3-12
DM total score	26.42	6.73	16-38
DM total score standard	8.92	3.09	5-15
Dm total percentile	39.23	30.39	5-95

**2. Possible associations between the perceived quality of life constructs and fine motor skills between them and with the other socio-demographic variables of the child**

The Pearson product-moment correlation was used to determine the strength and direction of the linear relationship between socio-demographic variables and fine motor skills or perceived quality of life of leukemia children. Significant negative correlation has been found between age and perceived quality of life ( $r = -0.76$ ;  $p = 0.04$ ), showing that a lower quality of life perception was associated with a higher age, so that the older the children perceived a lower HRQOL. Gender, risk band related to leukemia diagnosis and type of therapy they are going through (consolidation vs maintenance) are not significantly associated with the perception of quality of life in any of the PedsQL scales ( $p > 0.05$ ).

With respect to strength and direction of relationship between manual dexterity scores and the socio-demographic variables of the child (age, gender) no significant associations can be detected ( $r = ns$ ;  $p > 0.05$ ), while results of non-parametric statistical analyzes indicate significant differences in the average ranks of the raw scores of the non-preferred hand depending on the therapy phase (Mann Whitney  $U = 5.5$ ;  $p = 0.05$ ). Specifically, at the beginning of consolidation phase, children exhibit lower motor performance compared to motor functioning displayed in the maintenance (3.88 vs 8.39), so that it can be assumed that the toxicity of the initial chemotherapy negatively affects children's fine motor skills more in the first period of therapy than in the subsequent period.

Other significant associations were assessed between perceived quality of life and manual dexterity: there is a negative association between perceived quality of life perceived with respect to the physical area and manual dexterity relating to percentiles and standardized scores ( $r = -0.73$ ,  $p = 0.05$ ). Thus, parents declare a worse quality of life perception in the physical area in those children who performed lower in manual dexterity assessment.

**3. Stimulation activities for inpatients: description of possible benefits on quality of life, motor skills, parental and care staff appraisal of the kit and pleasure perceived by children**

With respect to psycho-educational play intervention and perceived quality of life of inpatients data collected do not indicate significant differences between children who performed the kit and those who did not. However, the present pilot study was conducted with a small number of children that were mainly in an intensive phase of therapy.

Comparing results of manual dexterity raw scores at T1 with fine motor skills performed after the psycho-education play stimulation intervention (T2), an average deviation can be detected, although with considerable differences at individual level. Three of the five children who participated in the study at the first evaluation (T1) achieved performance scores placed in the green zone of the MABC-2 (between the 25<sup>th</sup> and 75<sup>th</sup> percentile), while a child had achieved a score below the 5<sup>th</sup> and one above the 95<sup>th</sup> percentile, indicating in one case the presence of a significant motor difficulty, and in the other of a performance skill significantly greater than that expected for age.

At post-intervention (T2), on average, children show a deviation in the percentile of performance at MABC-2 of 17.6 points, passing from 47.4 to 65 (Table 4). In particular, two children achieved an improvement in the manual dexterity test. A child's performance remained stable, while the performance of two children fell slightly.

**Table 4** Descriptive analysis of variances in performance scores of ALL children in MABC-2 pre- and post-intervention

	T1	T2	Change
<b>Manual Dexterity</b>			
Mean	28.4	31.8	+ 3.4
Median	28	32	+ 4
Range	18-38	11	
<b>Percentile</b>			
Mean	47.4	65	+ 17.6
Median	37	63	+ 26
Range	5-95	54	

In the semi-structured COPM interviews, parents were asked (T1) to think about their child's daily activities and to identify the developmental areas more concerning. In addition, caregivers had to assign a score of importance to each activity.

The school activities mentioned by the parents are: write your name, cut with scissors, use the glue stick, hold the pencil and paint. In self-care dimension the following activities have been identified: unscrew the bottle cap, fasten the shoes, close the zip, use the knife, wear the shirt, put the toothpaste on the toothbrush and eat independently. The average importance attributed by participants to the self-care performance area ( $M = 7.88$ ) was lower than that considered with concern connected with productive educational activities rated important for future academic success ( $M = 8.86$ ). At T1, parents judge children performances at an average global level ( $M = 4.69$ ). Exhibited skills related to school productivity ( $M = 5$ ) are better than those related to self-care ( $M = 4.38$ ). These results correspond to globally high satisfaction levels ( $M = 7.52$ ), especially in school productivity ( $M = 8.29$ ) compared to self-care ( $M = 6.75$ ).

**Table 5:** Mean Productivity and Self-Care importance scores and mean differences between pre- and post-psycho-educational intervention at the COPM

Activity	Importance	COPM		M diff. T2-T1	COPM		M diff. T2-T1
		P T2	P T1		S T2	S T1	
Productivity	8.86	6.8	5	+1.8	8.2	8.29	- 0.09
Self-care	7.88	4.4	4.38	+0.02	7.4	6.75	+0.65

Note: COPM P= Performance; COPM S= Satisfaction; T1= pre-intervention; T2= post-intervention

Parents interviews with the COPM report some interesting qualitative data that should be considered. The totality of the parents reports that their child was very active before the onset of the illness, but he became tired, lazy and the desire to play diminished. Moreover, in the narratives of three out of five parents emerge that they are very satisfied with the commitment and motivation of children facing difficult activities, while the remaining two parents say that since the illness began, children often ask for help to carry out activities that they are actually able to do. However, helping children is not a problem because this kind of support and assistance "is a way to be close to them". Parents are likely to experience a high level of parental satisfaction in helping children despite the difficulties perceived in carrying out productivity and self-care activities. As stated by Mancaniello (Mancaniello, 2006), the concern about survival can lead parents to change their expectations in taking care of the child, replacing him even in those tasks that he could perform alone. Even for parents who participated in the present study, the diagnosis and treatment of a tumor affected activities, routines and habits related to learning and personal independence of the child, as described by Moruno and colleagues (Moruno Miralles et al., 2016).

After psycho-educational stimulation activities parents generally report a slight improvement in overall occupational performance (+0.91), which is associated with an increase in the area of productivity (+1.8) and self-care (+0.02). These ratings correspond to a slight improvement in satisfaction (+0.28), which relates to a slight lowering with respect to school activities (-0.09) and an increase regarding self-care skills (+0.65). These slight variations in the area of parents' perceived satisfaction are not surprising since, on average, there are not even high deviations in children's manual dexterity performances between T1 and T2.

The COPM is reported to be sensitive to changes in individual occupational performance (Carpenter, Baker, & Tyldesley, 2001; Sewell & Singh, 2016; Case-Smith, 2003; Nielsen, Andersen, Petersen, Polatajko, & Nielsen,

2019; Eyssen et al., 2011). The manual of the COPM states that the cut-off to detect a significant improvement over time is equal to 2 or more points of deviation from the initial mean ratings. A minimal clinically important difference of 1.4 points has been suggested for the COPM performance score based on a study with adults with specific health problems (Eyssen et al., 2011). Participants of the present study do not show from baseline to second assessment time point a mean difference greater than 2 points in the productivity domain nor in self-care dimension. The totality of the parents, during the interview with T2, claims to have noticed positive changes on the general well-being of their children. Despite the fatigue and side effects of the therapies, children often ask to play and build the kit objects together. For example, a parent during the COPM interview states:

"[...] at times when he doesn't sleep, he seems to me more smiling: he laughs, jokes and is amused when he takes part in the kit games. Despite the fatigue, after the activities she is satisfied and in a good mood. For a moment it seems to me to go back, when the disease was not there yet! "

A parent of another child makes it clear that:

"[...] compared to the past few weeks I see him more active and smiling. When this is the case, I forget for a moment of the place where we are";

The need for normality also emerges in a third interview:

"Since my son knows that in Day Hospital he can play with the kit, he is happy and peaceful, I see him laughing often, despite having to undergo visits and blood sampling that hurt him and scare him."

The statements reported here attest that the kit promotes a change of perspective in parents. The introduction of playful psycho-educational activities to stimulate fine and graphomotor skills leads parents to the pleasure of seeing their children in action and facilitates a dyadic relationship focused on play rather than on health conditions. The interviews with parents of leukemia children confirm the thesis of Polatajko and Mandich (Polatajko & Mandich, 2004), according to which being able to participate in occupational activities allows young inpatients to learn and develop physical, cognitive, social and emotional skills through action, to pose new challenges, to strengthen their self-esteem and self-confidence, a sense of belonging and social participation, that are fundamental issues for present and future health and well-being. On the other hand, parents' statements clearly bring out a need for normality that is expressed in the necessity of seeing and fostering the healthy part of their children even in a setting of care, in the requirement of dealing with the skills and competences demanded for re-entering in the world of peers. The concern for life outside and beyond the disease emerges repeatedly in the interviews with parents who have participated in the present study and it has become tangible in the repeated requests to health personnel for having at disposal different materials to enhance fine motor skills. In addition, one parent expressed concern throughout the COPM interview that his child, unable to go to school as his peers, would have encountered difficulties in learning to write.

Finally, a third parent claims that, after the onset of the disease, a pneumonia and a meningitis, "the child spent three months in bed, never being stimulated". Statements such as the latter report attention to the perceived need on the part of families to keep children occupied, to feel a "space of normality" in which skills and competences are still cared for.

The totality of the children (5 out of 5) states that playing with the kit was funny and showed to appreciate the psycho-educational activities. Moreover, they declare that the difficulty level was appropriate to their abilities. Four children out of five stated that they wanted to continue playing, and that they managed to make all the games

offered in the kit. So far, we can conclude that for the children, as well as for their parents the MoFis-I kit represented a globally positive experience.

According to the care staff interviewed, the kit has many advantages. First, the material is cheap and easy to find and the fact that it is contained in a box makes it plainly transportable. The psycho-educational activities are mostly simple to administer but sometimes instructions have been considered not adequate. Furthermore, administration time for some activities has not always been satisfactory because more time would be required to complete the games. Care staff respondents report that the moments during which the has been used kit were pleasant and that it was easy to involve children in the psycho-educational activities, because they are intuitive and enjoyable.

#### **IV. DISCUSSION AND LIMITATIONS OF THE STUDY**

Results of this exploratory study do not confirm the previous research, which detects fine motor difficulties after the re-induction phase (Reinders-Messelink et al., 2001) as well as in the maintenance phase (M. Tremolada et al., 2011), related to the age of the child at the time of diagnosis and the duration of hospitalization (Tremolada, Sbalchiero, Bonichini, Pillon, & Carli, 2011). However, we must take into account some aspects that affect the reliability of our data collection.

First of all, the test administration conditions may have altered the fine motor performance of our participants. Positioning in bed or tables that are not suitable for the height of children may have had an influence on their performance. Smith-Zuzovsky and Exner (Smith-Zuzovsky & Exner, 2004) showed that children aged between 6 and 7.6 without motor difficulties who have an optimal sitting position (size of tables and chairs corresponding to the height of the child, feet on the ground, knees at 90°, back against the backrest) get the best results in the digital dexterity tasks of the In-hand Manipulation Test- Quality section (IMT-Q) test compared to children who are sitting on a too large chair not allowing to get a stable and optimal position.

Furthermore, the secondary effects of cancer treatments involve in the young inpatients a great fatigue affecting their performance, which becomes fluctuating according to the time of the day chosen for fine motor skills assessments. Furthermore, the percentile score of the Manual Dexterity Scale of the MABC-2 is based on only three tasks so that the failure on a single task influences the global test result comparing with norm values. Finally, the distance between the pre- and post- intervention administration did not respect the minimum distance of six months recommended to avoid a bias due to the learning effect.

Despite the limitations outlined above, this study also presents novel elements and provides some indications on how to support leukemia children and their families. The introduction of the kit in a hospital setting clearly shows that offering stimulating psycho-educational playing activities help young inpatients and their parents to face the difficult time of hospitalization during cancer disease and treatments. Interviews with parents report their concern regarding the future life of children, the need to support skills that are required when coming back to school, the expressed desire to see young patients happy and active even during illness. Several studies have shown how important it is to intervene on the family as a system to support the resilience of cancer children (Marta Tremolada, Bonichini, Schiavo, & Pillon, 2012). In this sense, the kit responds to a deep psychological need that can activate resources and positive energies. The MoFis-I kit appears to be, according to parents and staff care

appraisals, as a positive and stimulating tool to be adopted in contexts of health care such as the oncological wards, because easy to use and pleasant for children.

Finally, the occupational related interventions, as suggested in previous studies (Taverna et al., 2017; Tremolada et al., 2019), can reduce the psychosocial impact during and after chemotherapy, promoting social inclusion and supporting children and their patients' families. For example, a pilot study demonstrated that home-exercise intervention during ALL maintenance therapy was feasible and had promise for efficacy (Esbenshade et al., 2014). Fine motor skills are sensitive to rehabilitation and targeted intervention (Dankert et al., 2003).

Berninger and Fuller (Berninger & Fuller, 1992), for example, suggest that handwriting may be particularly challenging for students who lack on foundational skills in writing. The transition from kindergarten to first grade is an important period to develop and practice fine motor skills. In an observational study on 4 years-old children Marr and colleagues (Marr & Cermak, 2002) reported that kindergarteners spent approximately half of their school day engaged in fine motor tasks (range of 36%-66%). About the 20% of these activities were paper and pencil activities for either play or learning (writing or coloring with a pencil, crayon, or marker, or painting with a paintbrush). Two years later, children in second grade were found to spend as much as 30-60% of their day participating in an activity that required fine motor skills, of which 85% involved paper and pencil tasks (McHale & Cermak, 1992). On the basis of above mentioned studies it could be hypothesized that children beginning the elementary school with important delays in fine and gross motor domains could be more at risk for academic achievement. Moreover, longer hospitalizations and necessary treatments contribute to limit the discovering of motor functioning at this age stage forcing the young patients to stay in bed, and to avoid social and physical contacts due to their immunocompromised status. For these reasons the kit MoFis-I could contribute to help children maintain a level of occupational activity during long hospitalization periods. Psycho-educational plays stimulate patients' fine motor skills and occupational performance related to the skills required in the healthy life. Furthermore, this type of stimulation allows parents to perceive their children most active and support their resilience to the disease. Finally, the kit appears to be an easy to use, pleasant, transportable tool, suitable for the hospital setting and enjoyable for children. Tools like the kit MoFis-I should be introduced in hospitals to offer children with cancer the chance to support their motor development, psychological well-being and perception of quality of life during long hospitalization periods, caring for those skills required beyond the illness.

## **V. ACKNOWLEDGEMENTS**

We gratefully acknowledge the support of families, children, medical and health care staff of the Pediatric Haematology-Oncology Clinic of the Padua Hospital that participated to this exploratory research. We are also thankful for the helpful comments received from the colleagues of Department of Psychology in Padua on the initial draft of the manuscript. This research did not receive any specific grant from public funding agencies, commercial, or not-for-profit sectors. The authors declare that they have no competing interests.

## **VI. DISCLOSURE OF CONFLICT OF INTEREST**

The authors declare that they have no conflicts of interest in relation to the present study.



## VII. AUTHOR CONTRIBUTIONS

LT, MB, MT and LS conceived and designed the study; MB and MT collected clinical data; LT, MB and MT analyzed the data; LS designed the kit MoFis-I playful activities; LT, MB, MT, and LS wrote the paper; AB, MCP and BT gave medical information and revised the final draft of the paper.

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