



Research paper

Complementary and alternative medicine (CAM) for children with special health care needs: A comparative usage study in Italy[☆]Livio Provenzi^{a,*}, Francesco Saettini^b, Serena Barello^c, Renato Borgatti^d^a 0–3 Center for the Study of Social Emotional Development of the at-Risk Infant, Scientific Institute IRCCS Eugenio Medea, via Don Luigi Monza 20, 23842 Bosisio Parini, LC, Italy^b Department of Pediatrics, San Gerardo Hospital, via Pergolesi 33, 20900 Monza, Milan, MB, Italy^c Faculty of Psychology, Università Cattolica del Sacro Cuore, Largo Gemelli 1, 20123 Milan, MI, Italy^d Department of Child and Adolescent Neurology and Psychiatry, Scientific Institute IRCCS Eugenio Medea, via Don Luigi Monza 20, 23842 Bosisio Parini, LC, Italy

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ABSTRACT

Introduction: Complementary and Alternative Medicine (CAM) is widely used by families of children with special health care needs (CSHCN), mainly as an integrative approach with regards to conventional treatments. Nonetheless, studies comparing CAM usage among families of CSHCN with different pediatric diagnoses are sparse. The present study aimed at investigating features of CAM usage among Italian families of CSHCN with different common pediatric diseases.

Methods: One-hundred and twenty-one families were interviewed about access to conventional treatments and CAM usage for the care of their children. Four groups were identified based on childrens' diagnosis: autistic spectrum disorder, cerebral palsy, genetic syndrome, and pediatric tumors. Main areas of investigation were pharmacological treatment, access to conventional rehabilitation programs, typology of CAM used, scopes of CAM usage, maternal perceived efficacy, CAM expenditure per month.

Results: Access to traditional pharmacological treatment and conventional rehabilitation was unrelated to CAM usage. Mothers of children diagnosed with autistic spectrum disorders were found to use more CAM, with higher economic expenditure and lower perceived efficacy compared to the other groups.

Conclusions: The present findings document different patterns of CAM usage among families of CSHCN with different diagnoses in Italy. Clinical and ethical insights for family–physician relationship are further discussed.

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1. Introduction

Complementary and Alternative Medicine (CAM) is defined by the National Center for Complementary and Integrative Health (NCCIH) as “a group of diverse medical health care systems, practices, and products that are not presently considered to be a part of conventional medicine” [1]. The use of CAM for children with special health care needs (CSHCN) has rapidly increased during last decades [2–5]. Previous research documented varying patterns of CAM usage in families of CSHCN with different pediatric

diagnoses [5,6]. Unfortunately, whereas previous studies did explore access to CAM within populations of children with specific developmental disabilities, there is a limited body of literature actually comparing CAM usage between families of CSHCN with different pediatric diagnoses. Nonetheless, each developmental disability is featured by unique care needs, so that parents of CSHCN with different diagnoses might be supposed to move toward different types of CAM with a widely varying set of healthcare goals [7]. Moreover, specific issues associated with CAM use in pediatric population (i.e., comparisons between different clinical conditions, parental perceived efficacy, economic burden of CAM, differences related to geographical area) have received limited attention and still warrant scientific investigation [7]. As comparative usage studies have been warranted in order to support pediatric integrative clinical practice [2], the present research aimed at comparing CAM usage among Italian families of CSHCN with different pediatric diagnoses.

Abbreviations: CAM, complementary and alternative medicine; CSHCN, children with special health care needs.

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1.1. Patterns of CAM usage in families of CSHCN

Previous literature has been mainly focused on families of children with four different pediatric diagnoses: autistic spectrum disorders, cerebral palsy, genetic syndromes, and pediatric tumors. The prevalence of CAM usage in families of children with autistic spectrum disorders is among the highest of any other pediatric population [8]. Families of children with autistic spectrum disorders reported a wide range of CAM types, such as diets, supplements, herbs, homeopathic remedies, music therapy [9–11]. Parents of children diagnosed with autistic spectrum disorders mainly refer to CAM to facilitate detoxification, to regulate the immune system and to modulate the gastro-intestinal functions [12,13]. For families of children with cerebral palsy, prevalence of CAM usage ranges from 27% to 35% [14,15] and the main scope is an integrative approach together with recommended conventional treatments [16]. CAM used by these families encompass massage, hyperbaric oxygen, hippotherapy, and osteopathy [14–17]. The abundance of body-centered CAM interventions for children with cerebral palsy has been linked to the physic impairments faced by these children [18]. Genetic syndromes are a heterogeneous category of chronic disabilities, encompassing several rare diseases. Previous research has focused mainly on children with Down syndrome, documenting that up to 76.7% of parents used at least one CAM treatment for the care of their child [19]. Children with a genetic syndrome are commonly treated with CAM therapies such as nutritional, massage, animal-assisted therapy, as well as herbal and oral supplements [18]. As for children affected by pediatric tumors, more than the 50% of families reported that they ever used or were still using CAM [20]. In a recent US survey by Ndao and colleagues [21], the use of mind-body therapies had a 4-fold increase from pre-diagnosis to on-therapy in a sample of children with pediatric tumor. Prevalent CAM treatments used by these families encompass vitamins and minerals, dietary supplements, acupuncture, and Bach flowers [22–24].

1.2. Parental factors and economic costs associated with CAM usage for CSHCN

Diverse parental characteristics and features have been found to predict the adoption of CAM treatments for the health care of CSHCN [5]. Parents who hold a more “natural” philosophy regarding health and disease are more favorable to CAM usage for themselves and for their children [25]. Moreover, perceived efficacy is a critical aspect facilitating parental demand of CAM, even in absence of clinical and empirical evidence of beneficial outcomes. For example, 50–78% of parents of children diagnosed with autistic spectrum disorders reported some benefits of CAM treatments for their children [10]. Families of children with cerebral palsy reported specific benefits of massage for relaxation, managing sleep and pain, and global effects on child’s quality of life [26]. Higher parental perceived efficacy has been reported in families of children and adolescents with pediatric tumors [20,21], with similar rates between different geographic areas [22]. It should be noted that parents seeking CAM treatments face relevant economic burden [24]. Unfortunately, previous literature on the economic costs of CAM for families of CSHCN is sparse. A recent investigation by Christon and colleagues [8] did not report the effective economic expenditure for families of ASD, despite 44.7% of families enrolled in this study stated that the costs to cover CAM treatments were difficult to meet. A financial expenditure of 500 euros was reported in a sample of families of children with tumor [24], but a minor portion of the sample spent more than 2000 euros. Despite it is plausible that costs of CAM might vary consistently with geographical regions and clinical conditions [27], to the best of our knowledge, no previous study investigated and

compared the costs for CAM among families of CSHCN with different diagnoses.

1.3. Aims of the present study

The present Italian usage study aimed at: (1) assessing the relationship between access to conventional care (pharmacological treatments and rehabilitation programs) and the amount of CAM used by families of CSHCN; (2) evaluating the role of parents’ attitudes toward CAM in affecting the amount of CAM used to improve their children health; (3) exploring differences in the amount, types and scopes of CAM used by families of children with four different pediatric diagnoses (autistic spectrum disorders, cerebral palsy, genetic syndromes, pediatric tumors); (4) investigating parental perceived efficacy and economic expenditure for CAM in families of CSHCN.

2. Methods

2.1. Participants

A cohort of 121 CSHCN and their parents were enrolled at the Scientific Institute IRCCS Eugenio Medea at Bosisio Parini (Lecco, Italy). The IRCCS Eugenio Medea is a major neuropsychiatric hospital specialized in pediatric rehabilitation and attracting many families of CSHCN from the entire Italian area. For the purposes of the present study, families were grouped according to children diagnosis in four groups: autistic spectrum disorders, $N=31$; cerebral palsy, $N=36$; genetic syndromes, $N=32$; pediatric tumors, $N=19$. Specific diagnoses included in each group are reported in Table 1. Three subjects were excluded due to non-specified diagnosis. These subjects did not differ from included subjects for any socio-demographic variable (i.e., patient gender, nationality, socio-economic level; educational level of the parents).

Table 1
Clinical characteristics of the 4 diagnostic study groups.

	N	%
Autistic spectrum disorders (N=31)		
Autism	23	74.2
Pervasive developmental disorders	7	22.6
Asperger disease	1	3.2
Cerebral palsy (N=36)		
Cerebral palsy	36	100.00
Genetic syndromes (N=32)		
Down syndrome	7	21.9
Chromosome aberrations	5	15.6
Cerebellar malformation	5	15.6
Williams syndrome	3	9.4
Charcot–Marie–Tooth syndrome	2	6.3
Congenital central hypoventilation syndrome	2	6.3
Arnold–Chiari syndrome	1	3.1
Charge syndrome	1	3.1
Glycogenosis	1	3.1
Guillain–Barré syndrome	1	3.1
Joubert syndrome	1	3.1
Kabuki syndrome	1	3.1
Ollier disease	1	3.1
West syndrome	1	3.1
Pediatric tumors (N=19)		
Meningioma	7	36.8
Cerebral tumors	3	15.8
Pilocytic astrocytoma	3	15.8
Hemangioma	2	10.5
Pinealoblastoma	2	10.5
Ependymoma	1	5.3
Glioneuroma	1	5.3

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