**Development and validation of a new instrument to evaluate caregivers’ adjustment to children’s chronic illness: The Family Adjustment Inventory (FAI)**

**Introduction**

Il messaggio che deve passare nell'introduzione è che il nostro articolo è originale quindi va dettagliato in che cosa è originale, inoltre deve contenere il "perchè" è importante avere a disposizione questo strumento (rispetto a quello che già è presente in letteratura).  
Dobbiamo metterla su un piano più pratico, non dare spiegazioni metodologiche sui costrutti, ma puntare sul fatto che non ci sono strumenti utili da utilizzare nel contesto ospedaliero, oppure ci sono ma non funzionano o hanno dei limiti (spiegare...).

Tutto quello che scriviamo va motivato con una ref alla letteratura (x es. Pincopallo ha fatto questo questionario in x maniera e così facendo ha risposto solo a x bisogno, quindi noi abbiamo fatto y. Non citare studi dicendo abbiamo fatto così perchè lo fa pincopallo)

copiamo linguaggio e termini dalla letteratura, ci saranno sicuramente altri studi fatti in contesti simili.

The  diagnosis of a chronic illness in childhood may be disruptive for families, affecting their functioning and challenging their  coping strategies (Johnson & Mendoza, 2018; Martin et al., 2012). It can directly influence family dimension, testing members’ role and requiring a reorganization of priorities and resources (Jones, 2012).

During the course of the illness, caregivers are actively involved in different areas of the child care, such as assisting him/her during therapies and rehabilitation either at the hospital or at home, and managing social, financial and emotional aspects of the illness. This kind of experience could represent a risk for the caregivers:, some of them show good adjustment to the child's illness, while others may find more difficulties (Toledano-Toledano & Luna, 2020).

Caregiving has been described by Aneshensel and colleagues (1995) as an “unexpected career” characterized by a process where an individual moves through different stages, requiring adaptation and restructuration of responsibilities over time. Caregivers' experience is described as  characterized by high level of emotional, relational and financial stress and uncertainty, conditions that may lead to confusion, anger, sadness, anxiety and hope for a XXX  (Johnson & Mendoza, 2018; Rodriguez et al., 2011; Melnyk et al., 2001). The chronic strains experienced by caregivers, defined as persistent objective conditions that require continual readjustment, repeatedly interfere with the adequate performance of ordinary role-related activities (Pearlin, Lieberman, Menaghan, & Mullan, 1981).

Given that a high caregiver level of emotional distress can affect the child's outcomes and general family adjustment to chronic illness, resulting in a poor family functioning (XXX),  the experience of caregivers has been of growing interest for clinicians and researchers. (Eccleston, 2015).

→ pensate che potrebbe essere utile cercare qualche studio che metta a confronto il caregiver distress nelle varie patologie croniche? Non so se esista…

→ Credo potrebbe essere utile dare una definizione di caregiver burden/adattamento alla malattia, così da poter dire andare avanti.

Some existing scales provide a valid measure of specific constructs connected with parental adjustments to child chronic illness such as  individual’s perceptions of his/her family based on the McMaster model (Epstein, 1983); the interpersonal relationships among family members (Moos, 1986); coping strategies (Carver et al., 1989;  Turner et al., 2012);  support satisfaction and support interactions (Bridges et al., 2002).

Other type of scales seem to be useful to detect issues in adjusting to specific medical conditions without having been tested on a wider range of chronic illness (Klassen et al., 2010).

Moreover other scales focus on the measurement of parental distress or the impact of stressful events on family functioning (Streisand et al., 2001; Creamer et al., 2003; Haskett et al., 2006; McCubbing et al., 1983; Hymovich, 1984; Stein & Riessman, 1980).

Despite the presence of some theoretical models in literature regarding the complex process of caregiving and adapting to a child or older disability and chronic disorders (King et al., 1999; Pearlin et al., 1981; Pearlin et al., 1990; Wallander et al., 1989; Wallander & Varni, 1992; Wallander & Varni, 1995; Wallander & Varni, 1998; Thompson et al. 1994; Sloper, 2000; Swore Fletcher et al., 2012; Stamataki et al., 2014; Sullivan-Bolyai et al.,2004; Pelentsov et al., 2015; Van Scheppingen et al., 2008), to our knowledge, none of the existing psychometric instruments aimed to evaluate caregivers’ experience and adaptation to illness, is based on on a strong theoretical basis previously discussed and applicable in the clinical practice. Due to the lack of a unique reliable instrument to assess the caregivers experience and adaptation, clinical studies need to use various psychometric instruments, each one assessing a dimension of the caregiving and family experience.

Among existing frameworks, the “Caregiving Process and Caregiving Burden” model (Fig. 1?) developed by Raina and colleagues (2004), appears the most complete. It has the aim of predicting profiles of stress situations and identify vulnerable families and was used to assess parents of children with cerebral palsy (Raina et al. 2004) and cancer (Klassen et al. 2011), showing that the correlation that emerged from the analysis provide evidence regarding the relationships between the model’s variables in terms of caregiver health and well-being outcomes; but was also used with parents of children affected by a rare disease (Gómez-Zúñiga et al., 2021), XXX.

This model is multidimensional, incorporates the advantages of the existing frameworks, updating them with the conceptual knowledge that has emerged from literature, selecting the most relevant factors and thus creating a more complete and understandable picture of the caregiving experience.  The model also allows to detect not only the direct relations between constructs and outcomes but also the indirect effects (Raina et al., 2004).

It includes the following six main constructs (see Fig. 1):

1. Background/context
2. Child characteristics
3. Caregiver strain
4. Caregiver intrapsychic factors
5. Coping/supportive factors
6. Caregiver health and well-being

Figure 1.

Immagine che contiene diagramma, Piano, Disegno tecnico, schematico

Descrizione generata automaticamente

Retrieved from: Raina et al., 2004.

In the complex context of hospital clinical practice, probing the caregiver’s adjustment to the child’s diagnosis appears essential. Faced with a large number of families who access hospital treatment because of a child’s chronic illness, the clinical psychologist needs to understand which of these have greater difficulties in order to calibrate his/her intervention and prevent complex outcomes. For these reasons, having a unique tool that might ease in identifying potential caregivers’ difficulties at an early stage, targeting interventions and preventing complex psychological outcomes, could represent an important help for the professional.

Therefore, the main aim of the current study was to develop and validate a psychometric instrument, named the “Family Adjustment Inventory (FAI)”, based on the “Caregiving Process and Caregiving Burden” model (Raina et al., 2004). This new self-report measure aims to help the early detection of caregivers’ vulnerability in the process of adjustment to their child’s chronic illness.

The present work shows the first part of the validation study, until the definition of the final version of the instrument. The second part of the validation process is ongoing.

**Methods**

Dobbiamo scrivere bene come sono state scelte le aree, gli item, come sono stati somministrati ai pazienti etc.. (questa parte deve valorizzare il nostro lavoro, perchè è un aspetto unico, non ci dobbiamo limitare a spiegare solo cosa abbiamo fatto ma va data importanza a questi aspetti perchè tutti gli articoli in letteratura sono fatti sul questionario somministrato ai soliti studenti universitari, mentre il nostro è diverso

The study was conducted from XXXX 2016 to XXXX at Meyer Children’s Hospital in Florence, Italy. Study protocol was approved by the Hospital Ethics Committee and written informed consent was asked to all participants.

The initial validation process consisted in X different steps: (1) Questionnaire development; (2) Data collection; (3) Statistical Analysis.

**Phase 1 – Questionnaire development**

***Theoretical study of domains and factor definition*.** An extensive review of the literature was conducted (Hoekstra-Weebers et al., 2001; Anthony et al., 2003; Steele 2003; Raina et al., 2004; Clarke et al., 2005; Raina et al., 2005; Barlow & Ellard, 2005; Nolbris et al. 2007; Bernardi & Badon, 2008; Coletti et al., 2008; Pettoello-Mantovani et al., 2009; Alderfel et al., 2010; Klassen et al., 2011; Long & Marsland, 2011; Pinquart, 2013; Long et al., 2014; McDonald et al., 2014) in order to identify the factors, supported by empirical research, representing each domain. The original domain of “caregiver strain/stress” was splitted into two different domains: “caregiving demands” and “perception of formal care”. The “overprotection” domain was added to the model. (Tab.2).

Given the different caregiving conditions due to having only one child or more than one and in order to reach a complete picture of the family experience in facing a chronic illness, a specific domain regarding the condition of siblings was added.

The outcome variables were not of interest in the present phase of the study, exclusively aimed at the development of the questionnaire.

**Table 2.** Domains based on the “*Caregiving Process and Caregiving Burden*” model for pediatric population (Raina et al., 2004) and related factors.

|  |  |
| --- | --- |
| DOMAINS | FACTORS |
| **BACKGROUND AND CONTEXT**  (Family social and demographic characteristics) | Inserire qui tutte le informazioni richieste nella scheda anagrafica |
| **CHILD’S CHARACTERISTICS**  (alterazioni funzionali e aspetti comportamentali del bambino, e percezione di vulnerabilità del bambino da parte del genitore) | 1) CHILD’S FUNCTIONING:   * danno funzionale (motorio, cognitivo, altri sintomi) * dipendenza dalla figura genitoriale nello svolgimento delle attività quotidiane   2) BEHAVIOURAL PROBLEMS:   * problemi comportamentali * disturbi della sfera emotiva * somatizzazione   3) CAREGIVER’S PERCEPTION OF CHILD’S VULNERABILITY |
| **CAREGIVING REQUESTS**  (aspetti oggettivi assistenziali e influenza della care su ruoli ed emozioni genitoriali) | 1) CONFLICT BETWEEN THE CAREGIVING ROLE AND OCCUPATIONAL ROLE  2) PHYSICAL/MEDICAL ASSISTANCE TO THE CHILD  3) CONCERNS ABOUT THE ILLNESS  4) EMOTIONAL BURDEN |
| **PERCEPTION OF FORMAL CARE**  (percezione della presa in carico da parte della struttura di cura) |  |
| **FATTORI INTRAPSICHICI**  **(**caregiver’s internal state) | 1) SELF ESTEEM:   * autostima generale * autostima legata al ruolo genitoriale   2) SENSE OF MASTERY:   * senso di padronanza generale * senso di padronanza in riferimento alla situazione di malattia del figlio   3) ILLNESS COGNITION:   * accettazione * percezione dei benefici * heplessness |
| **COPING**  (elementi relativi al fronteggiamento della malattia da parte del genitore) | 1) SOCIAL SUPPORT:   * supporto strumentale * supporto informativo * supporto emotivo * supporto affiliativo   2) FAMILY FUNCTIONING   * coesione * flessibilità * soddisfazione * comunicazione positiva |
| **OVERPROTECTION** |  |
| **SIBLINGS** |  |

The addition of the “Siblings” domain to the model led to hypothesize a preliminary version of two forms of the FAI that could represent the different caregiving experiences:

* FAI-O (Only child) for caregivers with only child, without “Siblings” domain
* FAI-S (Siblings) for caregivers with more than one child with “Siblings” domain.

***Item development and scaling*.** An initial pool of items was generated based on a careful screening of the existing psychometric instruments that describe each factor (cit.XX). This led to a drafted initial item wording, which was then reviewed and revised by consensus among all the research team members.

The questionnaire takes the form of a typical performance test, with items presenting descriptions of states of mind, beliefs, attributions and behaviours. Both positively (i.e. higher scores representing higher levels of family adjustment) and negatively (i.e. higher scores reflecting lower levels of family adjustment) worded items were formulated.

A 5-points Likert scale measuring agreement levels with item statements was chosen (mettere le opzioni di risposta qui).

FAI’s total score of each participant represents the actual level of caregiver’s vulnerability to the adjustment process.

***Focus group and reconceptualization of FAI*.** In order to represent the target population, parent couples or  single parent, belonging to the following ward to which his/her child refers for treatment, were involved:

1. Onchoematology
2. Neuro-onchology
3. Metabolic disease
4. Gastroenterology
5. Rheumatology
6. Diabetology
7. Nephrology
8. Cardiology
9. Cystic fibrosis

The inventory structure, each domain, factors and single items were discussed in a session of focus group conducted in hospital by two research psychologists.

The caregivers were asked to provide feedback on items’ completeness and comprehensibility in conceptual and linguistic terms.

After the focus group, the research team members discussed ideas and considerations that have matured during the meeting and the preliminary version of the FAI was completed: 182 items and 197 items were identified, respectively for the FAI-O and FAI-S inventory’s forms.

3 focus group

**Phase 2 – Data collection**

The study sample involved 600 caregivers of child aged 3-18 with a chronic illness being treated in the following hospital wards:

1. Onchoematology
2. Neuro-onchology
3. Metabolic disease
4. Gastroenterology
5. Rheumatology
6. Diabetology
7. Nephrology
8. Cardiology
9. Cystic fibrosis
10. Intensive care unit
11. Allergology
12. Immunology
13. Bronchology

Caregivers were recruited during children daily visits in Day Hospital or hospitalization. All of them provided written informed consent.

Exclusion criteria included: inability to understand written and spoken italian language, cognitive impairment.

The study sample consisted of two groups:

* 300 caregivers with only child
* 300 caregivers with more than one child.

All participants were asked to complete the FAI-O or FAI-S, depending on the composition of their household.

Caregivers of the same household could participate as separate subjects and completed the inventory indipendently from the other.

**Phase 3 – Factorial Analysis/IRT**

Each preliminary scale was then fit to a unidimensional two-parameter IRT model and items were iteratively removed based on their discrimination parameters, difficulty parameters, item information curves, and McDonald’s ω values, so that each preliminary scale had 10 or fewer items

🡪 ricordarsi di nominare il reverse nel calcolo del punteggio

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