

**CONSTRUCTING AN EXPLANATION  
OF ILLNESS WITH CHILDREN:  
A SAMPLE CASE STUDY OF JUVENILE ARTHRITIS**

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**BACKGROUND**

- Children's narratives about the illness use codes and modes that are often quite distant from an adult way of thinking (Bibace & Walsh, 1980; Capurso e Trappa, 2005; Bianchi di Castelbianco e al. 2007).
- Illness-informative activities have been proven to help children improve their understanding of illness (Eiser, 1989; Williams & Binnie 2002; Barlow & Allard 2004);
- Socio-constructivism states that children can actively build their own knowledge thanks to social interaction and thanks to the mediation of more capable people and cultural artifacts (Cole, 1997).

**OBJECTIVE**

- To develop an information book about Juvenile idiopathic arthritis that could be used in different ways:
- a tool to explain the illness to newly diagnosed children and adolescents;
- a medium to enhance communication between the patient, the family, and the treating physician;
- a take-home workbook.

## PARTICIPANTS

- 12 children and adolescents (Age range 4-14; Mean age 8,3; SD 3,3; 50% female) with Juvenile idiopathic arthritis.
- Enrolled through the local parents' association in Central Italy.

## METHOD

- A practical and interactive workshop, based on
  - A workbook created ad hoc by a comic books designer.
  - Methodology based on socio-constructivism and piagetian dialogues (Bibace and Walsh, 1980; Bruner, 2005; Vygotskij, 1934; Piaget, 1923).
  - Spontaneous children narratives, metaphors, drawings, creativity, free expression and active communication.

## METHOD: WORKBOOK'S OVERVIEW

- Mario Ask “what is Juvenile idiopathic arthritis?”
- Metaphor: *for me having arthritis is like...*
- After knowing he has arthritis, Maria has different thoughts...
- Things you can and can't do when you have arthritis....
- Today Mario does not feel well. *Where does it hurt?*
- When you are not well, *what do you do to feel better?*
- *What do you want to do when you grow up?*

Ciao io sono Mario... ieri sono andato dal medico e mi ha detto che ho l'artrite idiopatica giovanile. Io però non ci ho capito molto. Tu mi sai spiegare cosa è?  
Scrivilo qui sotto!

What is arthritis

IO PENSO CHE NON DEVI AVERE PAURA PERCHE IO HO AVUTO BISOGNO DI AIUTO PER IL GINOCCHIO E LA CAVIGLIA.

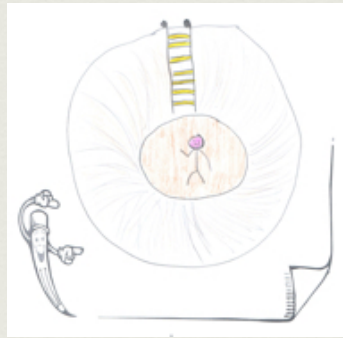
ARTRITE È UNA MALATTIA CHE PUÒ FARE MALE ALLE OSSA, E DIVERSE PARTI DEL CORPO.

CARO MARIO CO LA ANCHE IO LA STESSA MALATTIA SOLO DIVERZA

## the metaphors



having chains on your knees....



Fall into a big hole. There is only a small ladder to get out, but it is very hard for you to climb it.



a burning flame....

## RESULTS:

- The workshop allowed **89 children's comments** to emerge about arthritis, the constraints of illness, alternative activities when in pain, and also children's spontaneous definitions of the illness and their related feelings.
- All children talked in a free and relaxed way and actively contributed to the construction of the final workbook.
- Children listened to each other and expanded their knowledge and coping strategies.

## RESULTS:

- 32 pages booklet for newly diagnosed children
- the booklet is meant to be a facilitator of the communication within the family and with the treating doctor.

### Mario... e l'artrite



## RESULTS: A SAMPLE OF THE FINAL CHILDREN'S BOOK

Mario... e l'artrite

Quando si hanno dei dolori ci sono diverse cose che si possono fare per stare meglio

Ecco cosa dicono altri bambini e bambine come te. Fai una crocetta se ci sono cose che fai abitualmente anche tu:

<input type="checkbox"/> Vado a dire a qualche amico, amica, ai miei genitori o ai miei parenti cosa mi fa male.	<input type="checkbox"/> Mettere del ghiaccio sulla parte che fa male.
<input type="checkbox"/> Fare un riposino per dimenticare tutto.	<input type="checkbox"/> Andare dal fisioterapista e fare gli esercizi che dice lui.
<input type="checkbox"/> Prendere le medicine	<input type="checkbox"/> Prendere tutte le medicine che dice il dottore e riposarsi.
<input type="checkbox"/> Stare calmo.	<input type="checkbox"/> Ricevere dei regali.
<input type="checkbox"/> Sdraiarsi e non sforzarsi.	<input type="checkbox"/> Fare le iniezioni o prendere le pastiglie o le bustine.
<input type="checkbox"/> Massaggiarsi le parti che fanno male con la crema anti-dolorifica.	<input type="checkbox"/> Giocare con i genitori, un fratello o una sorella, oppure con gli amici per non pensarci.
<input type="checkbox"/> Pensare che presto si guarirà; avere fiducia in quello che dice la dottoressa.	

Il tu cosa fai per stare meglio quando stai male?

**I consigli della dottoressa Elisabetta:**

Ricordati che la ginnastica fa bene come una medicina! può essere anche una cosa divertente da fare con i genitori o con gli amici, magari mettendo della musica e facendo dei movimenti assieme.

I dottori sanno come curare questa malattia ma per farlo hanno bisogno della tua collaborazione! Prendere le pastiglie o fare le punture sono scocciare, ma servono per non avere più dolori, potersi tornare a divertire come tutti gli altri bambini e crescere bene.

Inoltre il dottore ti potrà chiedere di continuare a prendere le medicine per un po' di tempo anche se non hai più dolori.

Per guarire dall'artrite occorre tempo!

## CONCLUSIONS:

- Children can participate in the construction of the explanation of their own illness as active partners.
- Using proper mediators (i.e. workbook, workshop, an easy setting, consoling and listening attitudes) facilitates this process.
- Medical personnel can review and integrate the final product at a later stage, after children have expressed themselves;

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### Constructing an explanation of illness with children: A sample case study of juvenile arthritis

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#### ABSTRACT

This study aimed to create a book to explain juvenile arthritis to newly diagnosed children, starting with the narratives of currently ill children. The development of the book followed a socio-constructivist approach and occurred over several stages, including: design of a comic-based workbook; conducting a

#### KEYWORDS

Children; explanation of illness; narrative; socio-constructivism; juvenile arthritis; workshop

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