

GIVING CHILDREN A VOICE THROUGH ART: TO UNDERSTAND AND EDUCATE ABOUT THE IMPACT OF JUVENILE IDIOPATHIC ARTHRITIS BY CREATING ART AND TELLING DIGITAL STORIES



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OBJECTIVES



To describe a process by which children with juvenile idiopathic arthritis (JIA) create an art work and subsequent digital “health care narrative”

Specific aims:

- 1) To understand if such an expressive opportunity improves children’s health status
- 2) To publicize children’s art/stories to increase community education about JIA



INTRODUCTION



- Although nearly 20,000 Canadian children are affected by juvenile idiopathic arthritis (JIA), there is poor community awareness
- Children with JIA suffer from “invisible challenges”:
 - Chronic pain and fatigue
 - Limited participation in sports
 - Limited extracurricular activities
 - Daily medications
 - Blood tests
 - Other painful procedures
- There is a knowledge gap about how children cope
- Art therapy decreases patients’ stress and storytelling results in psychosocial benefits for patients. This combined approach has not been previously studied in JIA



PATIENTS AND METHODS



- Participants:** A prospective cohort of 10 children and adolescents (8 -18 years) with JIA participated in one-day art workshop(s)
- Each child subsequently produced a **digital story** about their illness experience using art, talking, writing and videoclips, assisted by a research assistant.
- Health related quality of life (HRQL):** Pediatric Quality of Life Inventory- (Peds QL) was used (“0” = worst and “100” =best HRQ).
- Individual structured interviews with the children were conducted following the creation of digital story.**
- Social media/public venues were used to exhibit children’s expressive creations.**
- This mixed methods study used philosophical hermeneutics for the qualitative methodology

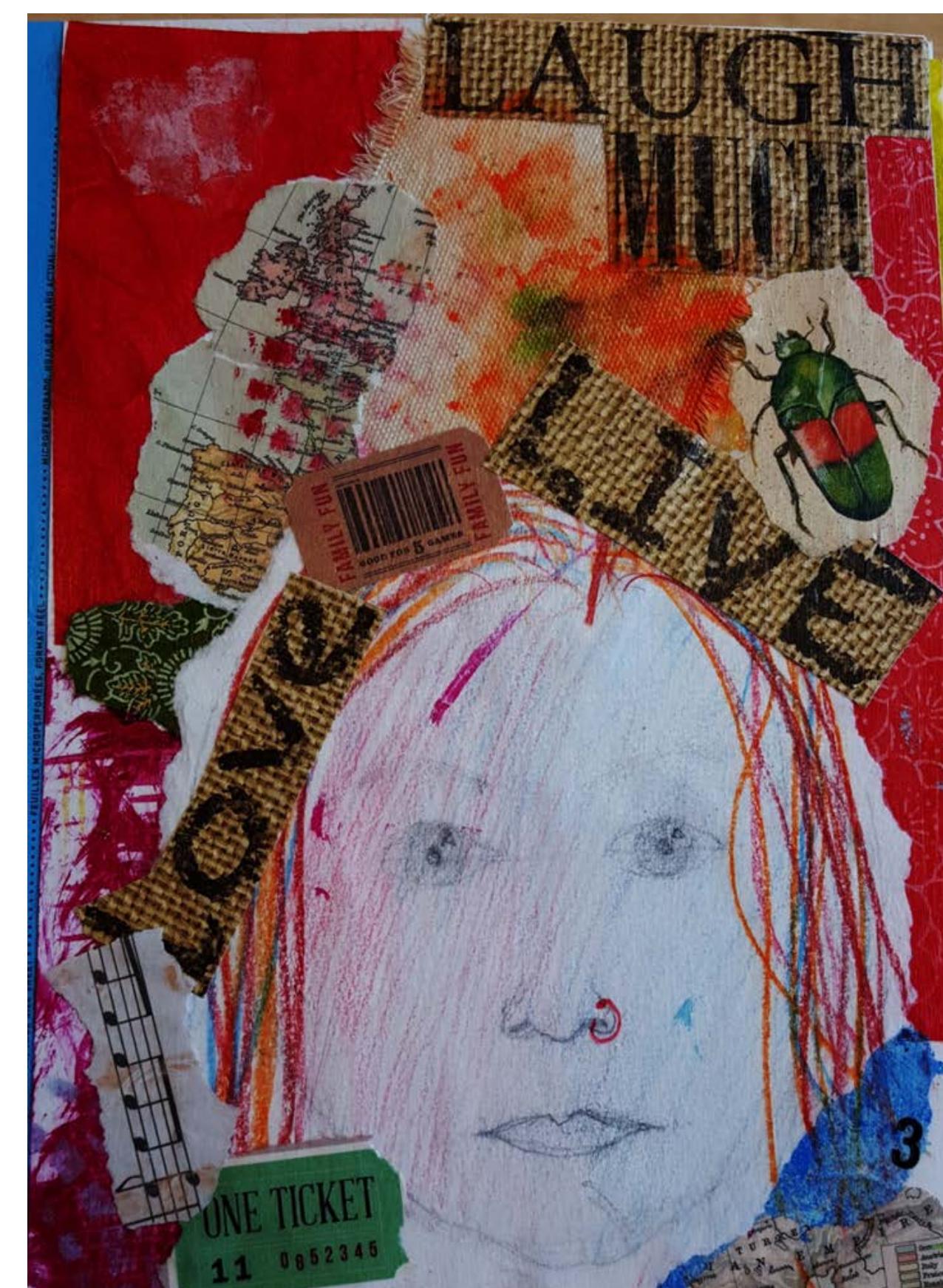


“Arthritis is random.
Sometimes it’s good,
Sometimes it’s bad,
Sometimes it’s all
swirled.”

Kaysa, age 10



RESULTS



- PATIENTS:** 10 children and adolescents were included (4 M and 6F). Each child created an individual art work that was subsequently used as a point of discussion in the digital story narrative
- HRLQ:** The pre-project PedsQL mean (range) scores for the 5 subsections:
 - 1) Pain and Hurt: 79 (19- 100)
 - 2) Daily Activities: 94 (55-100)
 - 3) Treatment: 77(32-100)
 - 4) Worry: 84.3 (33-100)
 - 5) Communication: 60 (0-100).
 - The scores were similar following the project
- Post project interviews :** All children viewed creation of art/digital stories as psychologically beneficial
- Knowledge transfer:** Public sharing of art work/story publicly shared (YouTube, TELUS SPARK, website, etc.)—all children consented



CONCLUSIONS



- Psychosocial stress and impaired functioning was present in JIA patients
- Creating art and of knowing “how to tell your story” was benefical
- The novel use of social/public media allowed for increased public education about JIA.
- LINKS:** <https://www.youtube.com/channel/UC3qTSN5BjIQEJ9lsy8kqRmw>
<https://drive.google.com/file/d/0B9z9i4XnE3jJOG9wbU5GcmdBSW8/view>

