

Meaningful-engagements with online museum collections for children with chronic health conditions

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Abstract

Recent research shows that children with chronic health conditions (CCH) often confront challenges that affect their daily activities and quality of life. As a result, in many cases, they experience high levels of stress. Research suggests that programs designed to reduce stress may help CCH and improve their quality of life. This article will support these recent findings by presenting a new concept and method (still in its pilot stage) that may help to reduce stress through a well-defined interactive process for CCH, designed to empower them and improve their quality of life. In order to better understand the concept and its context, this article will initially discuss a community outreach program, entitled 'OMSI' - Online Museum for Self Improvement. OMSI represents a new concept for an interactive online museum that is comprised of wellbeing techniques, works of art chosen from digitalized museum collections and activities that adopt an interactive exhibition approach. Moving on, the article will present STORIA, the case study that provided the inspiration for OMSI followed by a discussion regarding the pilot exhibition, 'Heroes of Today'. This exhibition focuses on empowering CCH and reducing their levels of stress through the utilization of a meaningful-engagement activity entitled, "Create Your STORIA". Following this, the article will discuss the relationship between art/images and wellbeing / empowerment. The discussion will include literature related to a recent case study entitled, 'Art at the Bedside' which was conducted in Strong Memorial Hospital in Rochester, NY. This case study used images of museum art works on tablets to create conversations with patients and their families; the results showed an improvement in the quality of life of hospitalized patients. Thereafter, the article will discuss the relationship between art/images and its effect on the brain, including literature related to the interplay between imagination, images and mirror neurons. The article will conclude with a presentation of the proposed next steps for the OMSI pilot, which aims to empower CCH.

Introduction

"When we are no longer able to change a situation;
we are challenged to change ourselves"

Viktor Frankl

Children with chronic health conditions confront challenges on a daily basis, some of which arise unexpectedly and may even result in emergency hospitalization. In a recent study conducted by Compas et al (2012), facing these challenges was shown to have a great impact on the levels of stress found both in children with chronic health conditions and their parents/caregivers. The study suggested that using models for managing stress may result in its consequent reduction and improve the quality of life of this community group (Compas, Bruce E. et al. 2012). The aim of this

article is to describe a new creative interactive model (still in its pilot stage), entitled 'OMSI' - Online Museum for Self Improvement. OMSI aims to address these challenges by providing meaningful experiences through an interactive exhibition approach. OMSI is based on a methodology called STORIA™. We hypothesize that taking part in these exhibitions may reduce stress, as well as empower and motivate participants to move forwards regardless of their life circumstances. The article will suggest that this may be achieved through the creation of a visual map portraying the journey to reaching one's desired aim(s), on the basis of the STORIA method (Salomon 2017). STORIA uses images and affirmations in order to create visual maps that guide participants how to practically move forwards and achieve their life aims. The STORIA method was developed by Eliron Salomon, this article's author and was based on her own life's circumstances, being a mother to a beloved child who is challenged by chronic health conditions requiring long term ventilation. Storia was first utilized in a case study of three children for a period of eighteen months in weekly sessions during 2008-2009. This paper will focus on an activity called 'Create Your Storia' which is included in the exhibition called 'Heroes of Today'.

During the preparation of OMSI's pilot exhibition entitled, 'Heroes of Today', several important questions were raised regarding the impact of art/images on empowerment/wellbeing. More specifically, can art empower the viewer? If so, what are the possible underlying mechanisms that can be used? Can curators choose empowering art from digital museum collections? If so, what are the criteria they need to achieve this with? What is the rationale behind using art collections as opposed to other images and drawings? Of note, the art used in this pilot was specifically curated from the Wellcome Collection's online digital collection: <https://wellcomecollection.org/works>.

OMSI – Online Museum for Self Improvement

The overall management of CCH is, in most cases, handled by the child's parents. These adults may well not have the medical background nor the capabilities to deal with the stress, complexity and hardship that comes with raising a child facing these medical conditions. Moreover, the emotional state of these parents, whose children in some cases face conditions of a life threatening nature, may be affected in a profound way. This can be either positive or negative, depending on an array of factors including the parents' psychological endurance, coping strategies, self-awareness and his/her attitude towards life. The children themselves may suffer from a range of stressful emotions including fear, anxiety, uncertainty, anger and frustration. Learning how better to deal with these stressors often involves the adoption of various psychological techniques, significant financial means and having the time to participate in courses or therapeutic processes. OMSI offers an accessible solution to dealing with these stressors for both children

with chronic health conditions and their parents, either while in the community or during periods of hospitalization. OMSI's unique approach is based on the utilization of interactive online exhibitions that incorporate stories, art, wellbeing methods and the act of sharing. It provides a personalized online platform that helps and empowers individuals who are facing stressful life circumstances and trying to cope with day-to-day challenges. OMSI strives to provide its users with a playful, interactive experience through which they can claim responsibility over their lives. As a result, the individual will become positive co-creators and co-curators of their own future and not victims of their lives' circumstances.

OMSI's and STORIA's Structure

OMSI is the community outreach branch of STORIA. As such, it uses the online 'STORIA platform', which is based on an innovative holistic approach.

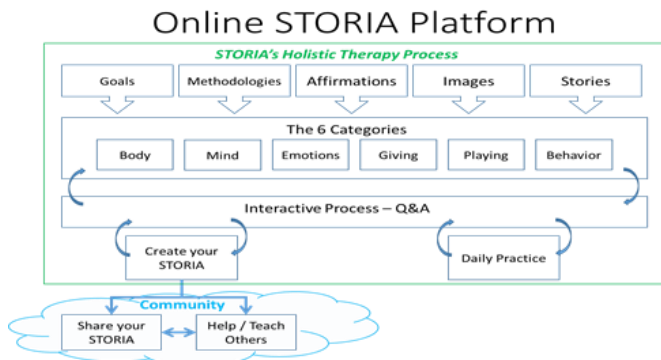


Figure 1. The Structure of the Online STORIA Platform

The online STORIA Platform, as detailed in Figure 1, presents a list of inputs such as Goals, Methodologies, Affirmations, Images and Stories. These inputs are assigned to six core categories that cover the fields that the user may wish to improve upon. It is practically achieved through the use of a series of questions that guide the user to create his/her 'STORIA', to develop daily practices which are aimed at achieving their goals and eventually, to share his/her story with the community and teach/help others.

As can be seen in the 'STORIA's Solution' below in Figure 2, the 'STORIA Platform' receives 'inputs' from content providers such as museums and content partners who provide practical methodologies to assist people in changing their lives.

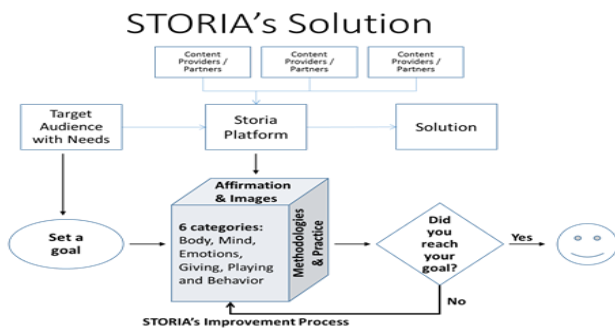


Figure 2. The Structure of STORIA's Personalized Solution

The users are requested to set a goal that they would like to achieve. They then enter into an interactive dialogue with the STORIA platform and in theory, undergo an improvement process until they practically reach the goal that they had decided to accomplish.

The process begins with STORIA's methodology where the user sets a specific reachable goal (a 'reachable goal' for this purpose can be explained as a goal that is challenging enough and yet reasonable, in order to avoid the inevitable frustration and disappointment of trying to achieve the unachievable) and then chooses an image from a digital art collection that represents the achievement of that goal i.e. how the individual see themselves in the future once their goal has been achieved. In the second phase the user 'creates his/her STORIA', whereby the user is asked to pick additional images and arrange them into a framework of six categories; mind, emotion, body, giving, playing and behavior. This initial setup creates the user's STORIA Map which guides the user as to how to reach his/her goal. The third phase includes an ongoing process that uses guided questions. These help the user to incorporate certain actions into their lives based on the images they have selected which reflect their desired futures. This is achieved via the use of the STORIA Map (see figure 3) through which the users are able to direct themselves in a positive and practical manner. The use of this map may provide the user with a visual clue and point of reference, which can stimulate 'a call to action'; the visualization of what the user wishes to achieve in their own life.



Figure 3. Children Co-Creat STORIA Map Exhibition
Source: Creative Director: Eliron Salomon, Drawn by: Yedidya Ish Shalom

The STORIA method was first utilized in a case study conducted during 2008-2009. The case study involved three children who were reviewed weekly for a period of eighteen months. Of note, these children were medically healthy and did not suffer from chronic health conditions. One of these children, in discussing the experience in her own words described it as follows: "Through this method I discover things that I would not otherwise be able to discover. STORIA provided me with practical tools (such as stories and characters) that help me to express my emotions and thoughts. STORIA helps me in times when I am sad and upset. The characters from STORIA are always on my side, they are with me and then I feel confident to do things that I usually do not do" (Participant, age 8, translated from Hebrew to English).

"Heroes of Today" – An interactive exhibition in a pilot stage designated for CCH

An interpretive plan for this pilot project (see figure 4) was developed over a twelve month period and is based on extensive operational experience in children's exhibition design conducted by Eliron Salomon in consultation with Liliana Reyes, children's exhibition designer from NYC.



Figure 4. OMSI's Inspirational Theme: *Because every child has a right to be happy*

The content of the pilot was based on the STORIA method (mentioned above) along side four wellbeing specialists: Patrizio Paoletti, Dr Jayant K. Bhadury and Hemant K. Bhadury (Bhriyu Yoga) and Lama Ole Nydahl (Diamond Way Buddhism and the Karma Kagyu Lineage). The art work for the exhibition was selected from the Wellcome digital collection: <https://wellcomecollection.org/works>.

'Create Your Storia' activity exposes the participant to six categories (Body, Mind, Emotion, Giving, Playing and Behavior). The unique combination of the six categories and the specific images that the participant chooses are collected into a 'Visual Map' that guides the participant towards the goals that he strives to achieve. The 'Visual Map' mainly provides a reference point and a field for the participant's experiments.

The proposed research will use design-research methodology. The goal of this activity is to explore the hypothesis that images and affirmation may assist CCH by empowering them to achieve a particular goal and as a result reduce their stress levels. Through a series of online interactive exercises the users will participate in 30-60 minute sessions in which they will use a handheld tablet in order to navigate through the application.

The aim is to create a personalized exhibition that reflects certain life goals and how to achieve them. An array of playful, engaging techniques will be adopted in order to guide the users through the session, including videos, sounds, words/sentences and images. The application provides a sufficient amount of time for the participants to make their own considered choices that truly reflect their thought processes: where to navigate within the application, what activity and images to use for their own STORIA exhibition, etc.



Figure 5. OMSI's Pilot – 'Heroes of Today' Interactive Online Pilot Exhibition Layout

Curating Art for Self-Improvement

Several questions arise when attempting to curate art for the use of self-improvement. How should the art be interpreted? How to find art that empowers and art that reduces stress within a large-scale digital collection? Do these two goals necessarily go together? In an attempt to answer these questions we turn to the lessons drawn from a recent case study, "Art by the Bedside" (Daiss, 2016). 'Art by the Bedside' was a hospital visitation program conducted over a six year period, beginning in 2009, with the opening of a dedicated palliative care in-patient unit at Strong Memorial Hospital, in Rochester NY. It involved volunteers who assisted patients in using an application on a handheld tablet at their bedsides. The authors of the study describe the program as one which, "uses the visual arts as a springboard for conversations with patients and their families. As a tool to facilitate conversations, 'Art at the Bedside' differs from the aesthetic and decorative objectives guiding placement of art work in hospital corridors and patient rooms. The practice evolved at the confluence of two disciplines: hospital chaplaincy and museum education" (Daiss 2016).

The results showed that the use of art/images provided the basis for conversation with patients and allowed them to see beyond the confines of their acute health issues. As the founder of the 'Art by the Bedside' program, Susan Dodge-Peters Daiss writes: "Over the past six years, bringing 'Art at the Bedside' to a variety of hospital and extended care settings, I have repeatedly witnessed the power of the visual arts to remind individuals that they are more than patients and to widen their focus beyond illness to reconnect to the truth of their fuller selves'... 'Art at the Bedside' is an unfamiliar activity and the images are in a computer and not immediately visible. A visual menu of pre-set image groups was developed to help explain the program as well as to give participants visual clues to help guide their selection. The potential of 'Art at the Bedside' as a starting point for conversation has proved itself repeatedly as a hospital visitation program, particularly as a source of diversion and distraction, but also as a

means of assisting patients to connect with and communicate about their experience with illness ... Accompanying patients and family members through the looking and reflecting process is an art in itself" (Daiss 2016).

Moving forwards to another subject of great interest to the discussion herein, is the question of what happens within the brain itself from a neuropsychological perspective when observing art and does an appreciation of this serve as a guide to the basis upon which the design of OMSI's pilot project should be built?

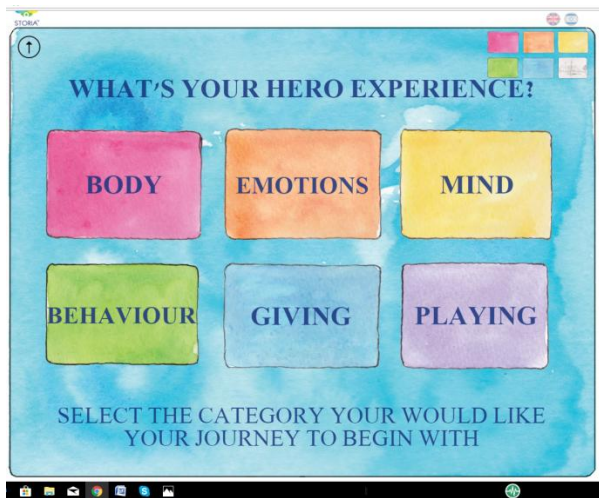


Figure 6. OMSI's Pilot –Interactive 'Create Your Own STORIA Exhibition' using 6 categories: body, mind, emotions, behavior, giving & playing

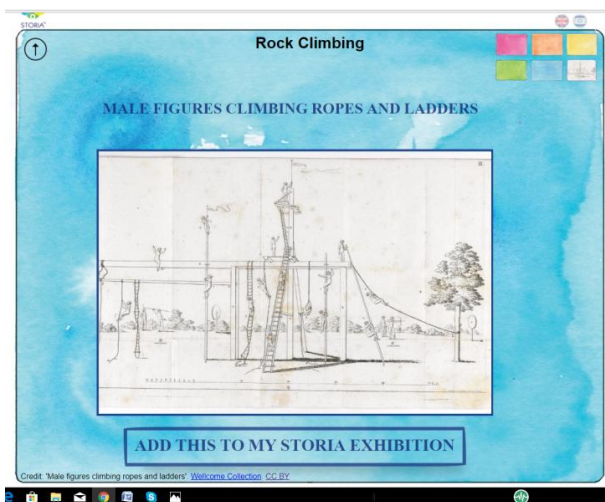


Figure 7. OMSI's Pilot – Interactive 'Create Your Own STORIA Exhibition'- choosing Art from the online Wellcome Collection

To broaden our understanding of this we turn to the work of Sandra Blakeslee and Matthew Blakeslee (2007). In their work, 'The body has a mind of its own', they describe the 'Mandela', a geometric pattern of shapes and images which represents the complex interplay of neural connections that connect the mind and body, shaping our actions. As they describe, "A Mandela is both an appealing metaphor and a convenient shorthand for referring to your brain's far-flung yet tightly integrated network of body maps." (Blakeslee & Blakeslee 2007). They contend that through

observing the actions of others, we become 'programmed' to simulate those actions. In their own words, Mandelas are, "The body maps that run simulations of what other people's body maps are up to". (Blakeslee & Blakeslee 2008, p166).

The work of Bedford also helps to further our understanding of the connection between art and neuroscience. In her book, 'The Art of Museum Exhibitions: How Story and Imagination Create Aesthetic Experiences', she writes, "The way we process information isn't just shaped by doing something physically with our bodies. Thinking about, imagining, and seeing someone else do a familiar action also affects us physically, and thus mentally; this is the work of mirror neurons". Mirror neurons, were first documented by Giacomo Rizzolatti in 1991. Rizzolatti found that "in the ventral premotor cortex (area F5) of the monkey there are neurons that discharge both when the monkey performs specific motor actions and when it observes another individual performing a similar action (mirror neurons)" (Rizzolatti et al 2003). "By modeling or simulating what other people are doing, feeling and intending, we are able to reach inside their minds" says Bedford and she adds that, "Mirror neurons enable us to understand and empathize with others" (Bedford 2014). Through this, we are able to see beyond our own realities and foster practical and emotional changes. As Bedford elucidates further, "We have come a long way since the days when mind and body - like imagination and reason - were considered distinct and unequal aspects of humanity. Now we know they cannot be separated. Story, imagination and the body are parts of the whole. Each reinforces the power of the others and each ultimately brings one back to the emotions. Exhibitions can reinforce the experience, the narrative, through the interaction of multiple bodily senses" (Bedford 2014). "Those at a 'high level of narrativity', such as immersive exhibitions, can become opportunities for the visitor to be so sufficiently engaged that they can become an actor in the story-world and move themselves through the story, shifting from conscious to unconscious engagement depending on their own narrativization of self" (Blakeslee & Blakeslee 2008, P.109 via Bedford 2014).

In addition to these research questions, there remains a further key issue that requires assessment, namely, what are the factors that make a piece of art 'empowering'? Connected to this, how can curators select such images and utilize them in a way that 'taps in to' the empowering potential contained within them? As described earlier in this article, the researchers intend to adopt the STORIA method in order to provide a relevant, accessible modality by which participants can build a practical road map to achieving their goals and foster change. The researchers intend to assess the effectiveness of this method through the use of questionnaires and interviews, through which they aim to gauge its empowerment potential.

Research aim and future steps

The aim of this research is to examine the question of whether art can empower the CCH and/or their parents/caregivers, reduce stress and increase a sense of competency? If so, does OMSI provide the mechanism to achieve this?

A separate discussion will be presented as to the effects that the exposure to art has on participants, in connection to the OMSI's

'Heroes of Today' pilot exhibition, including a description of its methodology, design-research approach, design epistemology and design praxiology.

Having better understood the value of using images as a platform upon which to inspire observers to change their behavior and achieve life goals, several questions are likely to arise regarding the curating process, pertaining to how best to select these images in developing OMSI's pilot exhibition, 'Heroes of Today'.

To this aim, we will explore the possible underlying mechanism of the specific modules introduced by OMSI on emotional functions. We will introduce OMSI's pilot exhibition to cohorts of CCH and their parents/caregivers following semi-structured interviews and questioners.

References

- [1] L. Bedford, *The Art of Museum Exhibitions, How Story and Imagination Create Aesthetic Experiences*. Left Coast Press, 2014.
- [2] J.K. Bhadury, *Sermon about Yoga*. Bhriгу Publication, Varanasi, India, 2011.
- [3] S. Blakeslee & M. Blakslee, *The Body Has A Mind Of Its Own*, Random House, 2008
- [4] B.E. Compas, S.S. Jaser, M.J. Dunn, & E. M. Rodriguez, (2012). "Coping with Chronic Illness in Childhood and Adolescence". *Annual Review of Clinical Psychology*, 8, 455–480. <http://doi.org/10.1146/annurev-clinpsy-032511-143108>
- [5] P. Dewey Lambert (ed.), *Managing Arts Programs in Healthcare*. Routledge, 2016.
- [6] Frankl, V.E., *Man's Search For Meaning*. (1959). Beacon.
- [7] Lama Ole Nydahl, *The Way Things Are, a living approach to Buddhism for today's world., Purpose, Pedagogy, Performance*. O Books, 2008.
- [8] P. Paoletti, *Growing Into Excellence, education for the third millennium*. Armando, 2008
- [9] Ferrari, P. F., Gallese, V., Rizzolatti, G. and Fogassi, L. (2003), Mirror neurons responding to the observation of ingestive and communicative mouth actions in the monkey ventral premotor cortex. 2003, *European Journal of Neuroscience*, 17: 1703–1714. doi:10.1046/j.1460-9568.2003.02601.x
- [10] E. Salomon, "Museums of the Future: A New Approach for Online Museum Collections in Interactive Exhibitions for Children in Hospitals", author & presenter at NEM Summit, Madrid November 30, 2017, <https://nem-initiative.org/nem-summit-2017-program/>

Author Biography

Eliron Salomon is the founder & managing director of STORIA™ & OMSI-Online Museum for Self Improvement. Eliron is an exhibition designer & developer, design researcher and lecturer. She is currently perusing her PhD in Museum-Studies at the University of Leicester (UK). Her research interests are in digital interactivity, art & wellbeing. Eliron holds a BFA with Honors from Parsons (NY) and MFA from Domus (Milan). Her BFA thesis was exhibited at the MoMA in NYC.