

Art and “the Language of Well-Being” in Adolescent Health Care[†]

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Abstract

Feeling effective as a young person depends on a capacity to draw upon one's own resources in the service of healthy living and development. In adolescent health care, there is the need to call upon the talents and creativity of young people, to introduce new and exciting experiences, and to facilitate involvement in their own care in order to nurture optimal growth and development on a physical and psychological level.

While hospitalisation can represent a major crisis point in adolescence, the provision of a stimulating environment and the opportunity for creative activities offers an exciting, transformative and healing experience. Art allows adolescents to use alternative languages beyond illness, to engage in endeavours that are distanced from overt therapeutic intent, and to embrace attributes of self-esteem and resilience. Through the process and production of art, and the inclusion of music, poetry, film or theatre, young people can experience personal growth, acquire skills, develop socially and contribute to environmental change.

In seeking to illustrate the value and importance of such approaches, this paper draws upon the experiences of a youth arts program attached to an adolescent ward. In a project called Art Injection, art students worked with adolescents to make sculptures from old hospital equipment, with startling results. More recently, the development of personal totem poles and an imaginative mosaic mural has powerfully engaged creativity and community in care. Group and individual art sessions, including the media arts project Creative Well, are offered on weekdays as part of the general hospital routine, enabling hospitalised young people to experience creativity as a daily part of their lives.

Ann Acad Med Singapore 2003; 32:71-7

Key words: Adolescent development, Art and health, Community, Creativity, Hospitalisation

Introduction

Creative processes involve imagining, making unexpected connections, maintaining discipline while letting go of controlling the outcome, opening oneself to pleasure, and moving beyond frustration. Creative activity parallels important strategies for mental and spiritual health—people who participate in well-designed creative processes report that it is powerfully restorative. Artists working in health can design projects that support people to experience the different dimensions of the creative process and set them up for success and discovery.

Art and healing have been aligned throughout history. At one time, healing itself was considered an art. Many traditional societies and the alchemists perceived art and

medicine as inseparable. Ever since the conceptual division of the arts and sciences in the Middle Ages, the arts have had a role to play in medicine. In contemporary society, that role is growing. Art is being recognised as having a fundamental contribution to the healing process. Artists are being employed to work within hospitals directly with the patients, staff, spaces, and culture of the institution.

The growing role of the arts in health care is the outcome of changes in attitudes and practice in the modern healthcare system. First, a shift towards treating the whole person rather than only the diseased or damaged parts and secondly, a greater understanding of the impact of environment on well-being. Acknowledging the power of artistic creation in the healing process does not signal a conversion to an

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[†]This paper is based on a presentation given at the VII International Congress of Adolescent Health in Salvador, Bahia, Brazil.

alternative medicine, but rather an acceptance of the place of the arts in the provision of integrated health care.¹

In this paper, we draw upon the experiences, both routine and special, of a youth arts program attached to an adolescent ward, and explore the benefits to young people and their healthcare providers of working collaboratively with “the language of well-being”.

Creativity in care

Hospital “is both a place to be born and a place to die; a place of healing and a place of pain; a place of the unknown and alien”.² Hospitalisation causes special difficulties for young people. Separated from friends, school and family, concerned about their illness and implications for the future, teenagers in hospital are frequently stressed and anxious. Those who have regular or long-term admissions for chronic illness may have difficulty accepting themselves, relating to others, and anticipating what lies ahead. The opportunity for hospitalised young people to engage in expression of feelings and exploration of creativity is central to promoting and supporting their health and development.³

Since its establishment in 1977, the Department of Adolescent Medicine at the Royal Alexandra Hospital for Children (now the Children’s Hospital at Westmead) in Sydney, Australia, has concerned itself with the impact of hospitalisation on adolescents. Even during the decade prior to the opening of a dedicated Adolescent Ward in 1987, the department facilitated responsive activities for inpatients, offered a range of contact options via a multi-disciplinary team, encouraged self-determination, and established peer support services.⁴

Innovation is well recognised as an integral aspect of adolescent health care. Accessible and effective services for young people tend to incorporate creative approaches, using the arts to encourage and facilitate youth participation, provide flexible youth-oriented environments, and reflect an awareness of youth culture.⁵ Such philosophies have underpinned the evolution of adolescent services at the Children’s Hospital over the past two decades.

One of the department’s pioneering initiatives was the establishment of a broad-based Youth Arts Program in 1986. The key professionals involved have been artists and occupational therapists, often working collaboratively to coordinate creative activities in consultation with the hospitalised adolescents who attend the Program. The occupational therapist contributes skills in promoting independence and social interaction, while the artist brings creativity to life and encourages cultural expression. The roles of these workers is multi-dimensional, ranging from intensive work with individuals, to facilitating group programs, to organising community cultural development

projects within the hospital. Through the Youth Arts Program, young people engage with artists and health professional staff and are sustained and supported by this process.

The Youth Arts Program provides an innovative approach to promoting adolescent health within an institutional environment. Over its sixteen-year history, the Program has achieved local and international recognition for art practice within a healthcare system, generated widespread media attention, produced a variety of challenging works and, most importantly, inspired many chronically ill young people.¹ Within the hospital, the Youth Arts Program focusses on the whole person, transcending the limitations of disease/disability/diagnosis or discipline. It exists comfortably alongside and integrates with other aspects of inpatient care.

Art, Health and the Adolescent

Participatory arts programs have benefits for patients, staff and the hospital. This is particularly true for the adolescent. For these patients, participatory arts can improve self-esteem by enabling young people to make a contribution, address social needs, instil feelings of wellness, support decision-making and independence, offer new opportunities and skills, balance an otherwise illness-oriented experience, and improve the atmosphere on the ward.⁶

Expression/Communication

For the hospitalised young person, the process of creation can allow a catharsis of suppressed emotion, the safe expression of fears of the forbidden, an exploration of possibilities (in art there are no handicaps), the experience of variety and challenge, and the creation of metaphor for interpreting the world.⁷ By stimulating self-expression and self-reliance, the artist can facilitate communication between young people and healthcare providers. By focussing on positive abilities and allowing participants control of the process, the artist models the possibility of actions being able to bring about change.

“After being involved in an act of artistic creation, we view the world differently. Our sense of ourselves as active creators is enhanced and we are more likely to view the world as malleable.”⁸

Example

Kane was a quiet, 17-year-old boy with cystic fibrosis. He had an enormous artistic talent. During one of his many admissions, he was given a hospital sheet to paint on and produced a work of haunting significance, both for him and his audience. He called it “Tear of Thought”. In one corner,

there is the faint image of a face, fading into clouds. The main feature is the face of an old man, tears flowing onto his cheek, sinking into water. The creation of this painting gave Kane the opportunity to talk about his experience of illness: “This painting represents the helplessness of life slowly fading away. The loss of identity, becoming something you once would not have recognised. There is a need for expression that comes from being trapped inside a world of unescapable sickness and continuous hospitalisation.” (Kane at 17 years)

“Art is communication—a person can gain insight both intellectually and emotionally by connecting the meaning of the image to his/her own life situation. By focussing on the image, many aspects of ourselves, previously hidden, may become clear. The person learns through the activity of creating something.”⁹

Place/Transformation/Power

The concept of environment is fundamental to the Youth Arts Program. This idea of environment goes beyond that of the architectural spaces where projects are sited. Our notion of environment is the sense in which a broad range of project participants experience it—physically and spatially, institutionally and clinically, hierarchically and emotionally.

“In responding to the immediate environment of the hospital, the artist can inspire the participation of the community in the transformation of the space. Young people are encouraged to explore their relationship with their environment, to understand it, speak about it, and to change it.”¹

Peer Group

A peer group context is important in the development of the adolescent and groupwork is an integral part of the Youth Arts Program.

“In groups they have the opportunity to share ideas, exchange experiences, identify issues, validate each other, determine their contribution and decide on action. By learning and sharing with one another, they develop the confidence to express their ideas in wider forums—communicating with their healthcare providers and participating in the community.”⁷

Fun

An exploration of fantasy and imagination as coping mechanisms, and the concept of fun as a healing force, are all elements of the Program.

Arts in health projects also have benefits for the staff and the hospital. For the staff, these projects can improve morale by improving staff/patient communication, help to present the patient as a whole person, not just an ill body, give staff the opportunity for their commitment to quality to be recognised, offer new opportunities and skills, and develop pride in their ward and its culture.

For hospitals, the process can present a positive image of quality service to clients, bring a greater awareness of the environment to public and staff, reduce physical abuse of buildings, and strengthen partnerships with the community.⁶

The descriptions of projects that follow capture a range of creative structures and of experiences of young people involved in the Youth Arts Program. They demonstrate how, through both the process and production of art, and a focus on well-being, young people experience personal growth, acquire skills, develop socially, and contribute to environmental change.

Special Youth Arts Program Projects

Art Injection 1991–1992: A milestone in the Youth Arts Program

The “Art Injection Project” was conceived by sculptor Amanda Buckland. It was initiated during discussion with adolescents about long-term hospitalisation, invasive procedures and “technological treatments”. It grew to involve students from Sydney College of the Arts working in teams with patients to explore the relationship between the body and technology. Defunct hospital equipment and excess apparatus were recycled to create a range of interactive sculptures and visual images.

The project allowed two diverse communities to explore and exchange the shared experience of confronting an alien environment. The artworks evolved from group discussions, responses to sites within the Hospital, and manipulation of materials.⁷

Example 1

Mark was a 16-year-old boy with cystic fibrosis. During the “Art Injection Project”, he had the opportunity to work with an art student on advanced computer art and animation skills. They worked together to create an image diary representing his current admission to hospital. His initial drawings included his infusaport and the insertion of a long line. His work titled “Minor Irritation” depicted an episode where a nurse struggled to find a vein to insert his long line. A clenched fist looms from a huge black void, huge leeches suck on his arm as blood drips into a fluorescent pool. As Mark’s skills developed, he began to animate and generate sound to create sequences of stories. He subsequently decided to become a computer artist and enrolled in a visual arts course at a technical college.

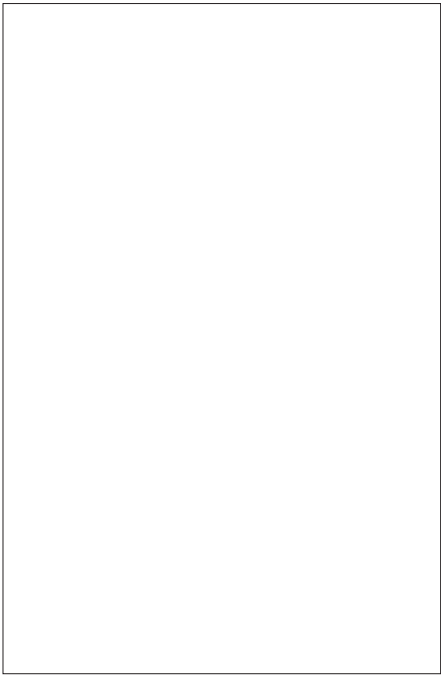


Fig. 1. "Walking Wheelchair" (1991–1992).

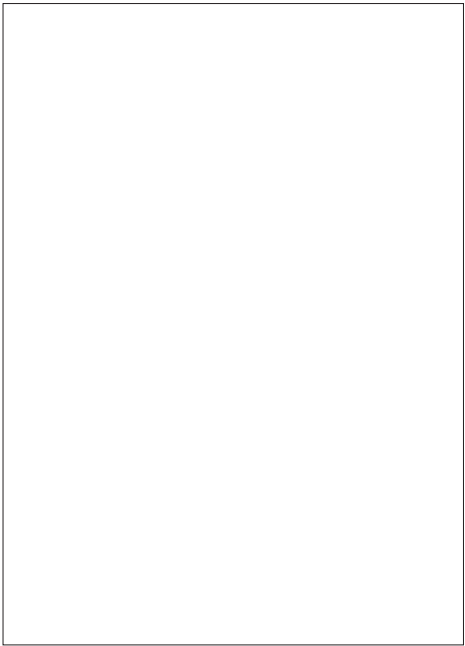


Fig. 2. "Giant Doctor" (Shalee 1991–2).



Fig. 3. "Totem" (1998).

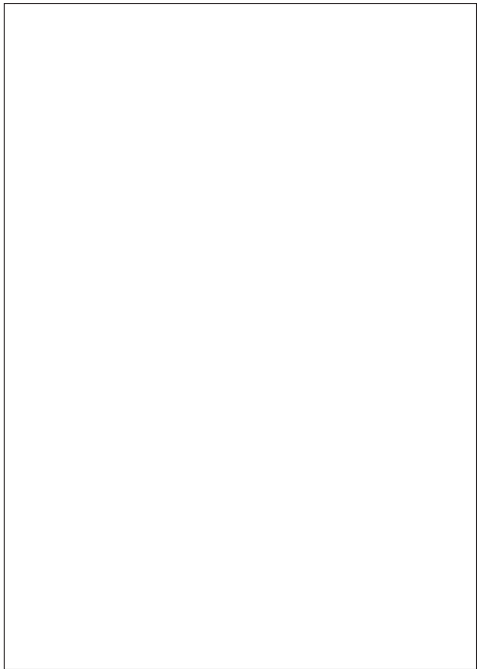


Fig. 4. "Totally Mosaic" (Jessica and Rachel, 2001).



Fig. 5. "Totally Mosaic" (2001).

Example 2

Two young women, confined to wheelchairs by the debilitating effects of juvenile rheumatoid arthritis, had been in hospital for several months. The “Art Injection Project” provided a much needed creative and emotional outlet. Working in a team with two artists, they created a pair of “Walking Wheelchairs” wrapped in plaster bandages (Fig. 1). One old wheelchair supported a long tube with two feet, which could be wrapped, dragged or cradled by the chair. The weighing chair was upholstered with an enticing array of soft teats. These severely disabled teenagers may have been commenting on their relationships to their chairs—how hard and unyielding they were, and yet how fragile and skeletal too. They became “fantastical carriages” with a life of their own.⁷

Example 3

Shalee had been a regular inpatient, experiencing lengthy admissions over a period of five years. The collaborative work, entitled “Giant Doctor”, had legs consisting of three storeys of crutches, his body was a miniature torso and he had no head (Fig. 2). His white coat was torn open to reveal a chest erupting with electrical wires. This work created a sense of anonymity and superiority. In creating “Giant Doctor”, Shalee was able to communicate the inequities of power and status that dominate hospital life. In her own words: “Before I did Art Injection, I didn’t realise that art was about feelings. I thought it was just paintings of an object that you thought looked good. I only realised that it was about feelings when we made the 12-foot high doctor that stood over the patients with his internal side looking like a mechanics workshop.” (Shalee at 16 years)

The power and presence of these images stimulated responses throughout the hospital. The sculptures became symbols of emotions and experiences, and evidence of collective action in an institutional environment. Their creation transcended barriers, allowing people permission to communicate about their feelings, fears and frustrations.

In 1995, the hospital moved to a spectacular new building, itself a work of art and a tourist attraction. The Children’s Hospital at Westmead even has its own art collection and curator. Within this creative and imaginative environment, the Youth Arts Program continues to have its special impact on all concerned. Youth Arts initiatives include major sculpture projects such as “Totem”, community cultural development projects like “Totally Mosaic”, regular Youth Art groups held as part of the adolescent inpatient Groupwork Program and individual art sessions with young people who have an active interest in art, or something special that they want to say. The Department of Adolescent Medicine also hosts a unique, independently funded hospital-wide art project called “Creative Well”.

“Totem Project” (1998)

In the “Totem Project”, 30 young people worked with artist Helen Pynor to create totems of themselves (Fig. 3). Drawing on the history of totem-making, the project encouraged young people to express and honour themselves by creating a symbolic representation of the self. The project allowed participants to access the process at different levels of self-disclosure or secrecy, according to the young person’s comfort level.

The works spoke for and about the young people. For some, the totem appeared to be an image of their vulnerability or anger, or an expression of a desired or fantasy self. For others, the process and methodology of making and constructing the pole seemed as strong a self-portrait as the finished piece itself. Although the works invited speculation, they were not used in a therapeutic or diagnostic framework. They remained works of art with the young people retaining final ownership of their meaning. The poles were presented to a broader audience in a public exhibition and are now on permanent display in the hospital where they stake out a clear territory, signalling the presence of young people in a colourful and energetic way.

“Totally Mosaic” (1999 to present)

In the courtyard shared by the Adolescent Ward and the Department of Adolescent Medicine at the Children’s Hospital at Westmead, a large-scale mosaic work is slowly crawling along the retaining walls that border the garden. Under the direction of artists Helen Pynor and Penny Thwaite, a wide range of people are participating in its creation, including hospitalised young people, nurses from the Adolescent Ward, staff from the hospital at large, and young people from groups and schools within the local community (Figs. 4 & 5).

Hierarchies in general, and hospitals in particular, separate groups of people by intensifying differences in status among the various professions and between professionals and patients. Creativity in the form of innovative, non-medical projects can be a powerful tool for building new relationships between people who would not normally come together. These facilitated collaborations can cut across the hospital structure by pulling together literally anyone who is housed under its roof at that moment in time. In this process, people talk to each other, often for the first time, and begin to manifest new kinds of conversations.

When people collaborate, they need to communicate with each other and to feel a sense of equality. Artistic collaborations can side-step these entrenched or inequitable relationships often experienced in health institutions by altering the basis for expertise and encouraging people to communicate in new ways. A healthier model of community—listening, imagining and talking—can be created and

promoted. For young people in hospital, participation in such a “creative community” supports them in keeping their link to normality, to their own strengths and skills, and to the outside world. It allows them to relate to staff around art processes rather than therapeutic processes, walking out of role as “unwell patient” and into role as “maker”, on an equal footing creatively with anyone else in the hospital. Young people can thus participate in and witness alternative, more equal models of a community functioning.

“Creative Well” (1997 to present)

“Creative Well” is a media arts project focussing on children and young people with recurrent and long-term admissions to the hospital. Helen Zigmond, who had been an arts teacher and consultant at the hospital, established the project in 1997. Through the use of story-telling, illustration and film-making, the project creates the opportunity to use alternative languages beyond illness in the hospital context—through the construct of “the language of well-being”. The challenge is to “tuck in behind the illness and find the young person still present”, to provide a voice and role beyond illness that is removed from the often exhausting process of therapy. In other words, “Creative Well” speaks directly to the artistic imagination of young people, alive and intact in bodies that are very often unwell. Involvement allows them to be proactive, to inspire others and move away from the role of passive receivers.

“Creative Well” is concerned with sustainability and in setting up a cultural context for hospitalised children. A young person’s participation is part of a collaborative protocol, contributing to a collective landscape from which others can draw inspiration and respond. The work is viewed as existing in the present, but also as part of a continuum—everything is considered a “work in progress”. Involvement is based upon the concept of “acceptance”, of freedom from pressure and assessments. Younger patients write stories that are illustrated by adolescent patients. The stories are frequently about animals, never about illness. Both the children and the teenagers gain from this relationship based on creativity rather than illness. Once illustrated, the stories are voiced by Helen and screened on the hospital’s closed circuit television, the Starlight Channel. The film-making in “Creative Well” is called “Scene Here” and explores the hospital environment as a positive and creative resource. Whether working individually or in group workshops, in producing “moments in film”, the adolescent participants develop skills in script writing, story boarding and the manipulation of a visual language.

Example

Every morning, when 12-year-old leukaemia patient, Ashley, woke to face another day of chemotherapy and

radiation, she wasn’t thinking about the gruelling hours of treatment. Instead, her thoughts were focussed on completing drawings for the book “Putting Time to Bed”—a collection of stories written by hospitalised children. “It took my mind off the illness,” she recalled. “Writing a cartoon story is like make-believe; you can make it how you want. In make-believe, there is no pain and sickness. You can be free.”

Four years later, Ashley was in remission, back at school and holding down a part-time job. She credited the project with helping in her recovery and giving her a sense of direction.

As Helen Zigmond explains: “Creative Well allows children and young people to be who they want to be, instead of being their illness. The power of imagination is both healing and essential to recognising who they really are...it allows them to see themselves as ordinary kids who have dreams and aspirations.”¹⁰

“Music and Mess” (2000 to present)

Artist Penny Thwaite devised “Music and Mess” as a structure for art-based groupwork with hospitalised adolescents. It was developed to meet the Friday afternoon needs of hospitalised young people whose regular weekly program comprises hospital school in the mornings and adolescent group in the afternoons. It attempts to mimic the school world outside of hospital, where Friday afternoon is often seen as a more relaxed time when recreation, sport or art activities may be scheduled.

In “Music and Mess”, young people are encouraged to bring their own music (tapes or compact discs) and their own art projects (unfinished, evolving, or ideas for projects not yet started) and to work with an artist, who is also trained as a groupworker. The artist thus operates as a personal art facilitator for the young person within a group setting. In some instances, the artist needs to work intensively with a young person to help them initiate a project, experiment, and then follow through. In other cases, only minimal input is required. A useful strategy has been to supply a range of materials and utilise processes that help stimulate the young people’s ideas and creativity.

Young people engaged in “Music and Mess” are encouraged to feel a sense of community and relaxation in a shared space, an environment that welcomes their own musical preferences and their own personal projects. In this freer setting, they are encouraged to self-initiate, ask for help when needed, relax, try things out, communicate, and make plans to complete their project if possible. The group’s timing means that the young people will often have some creative work to continue with over the weekend, which can be a time of decreased stimulation for them.

The young people have responded well to this structure which supports their self-esteem and creativity as individuals within a youth-friendly peer group environment, and offers the skills of a professional artist to assist them to realise creative projects. "Music and Mess" focusses on the young people's wellness within a hospital setting and helps develop their creative skills.

Conclusion

Arts projects can address life both at the personal level, by focussing on the expressive and independent self, and the community level, by challenging values, interpreting relationships, and opening communication. The individual is empowered as an active, creative subject. The group, by identifying common issues, is enriched as it interprets and creates its own culture. The collective experience is central in addressing the patients' sense of isolation and powerlessness. It allows those involved to share ideas, identify issues, validate one another, determine their role, and decide on a course of action.

The use of art in adolescent health care is a particularly empowering form of youth participation. Through active involvement in the sorts of arts projects we have described, young people can experience a greater awareness of themselves and their relationship to the world at large. As participants recognise their strengths and abilities, safely express their feelings and ideas, and question their role and relationships in the social system, they are encouraged to take actions based on this reflection.¹¹ If they emerge from hospital as confident, critical, and creative thinkers, they have the power to enact their potential throughout their lives, an exciting prospect whatever the prognosis of the illness.

Beyond these individual benefits, creative arts now represents a vital component of integrated, comprehensive health care for young people, epitomising the profound principles of creative change and self-healing. Future developments are being directed towards policies concerning the broader relationship between arts and health, a movement gaining momentum throughout the world.¹²

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