

Granting wishes to terminally ill children

A rite of passage

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Parents and care providers often struggle to give meaning and support to children in the terminal phase of their disease. What are these children's needs when hope for a cure fades and how can they continue to make their lives meaningful? Recently, volunteer organizations, such as the Make-a-Wish NL Foundation, have organized services to fulfil these children's last wishes. When children are approaching death, parents and care givers can experience anxiety when speaking about serious matters and considering the child's future. Can the child's serious disease be forgotten for even a moment? When a child's wish is granted by one of these organizations, temporal negation of the disease allows for a happy experience. The wish can be considered as an ante-mortem ritual. Action with respect to a seriously sick, and sometimes both mentally and physically handicapped child, cannot be undertaken without adequate preparations. It requires careful cooperation between families, hospital and volunteers. The fulfilling of a wish can be considered as a 'rite of passage' and the remembrance of the event will be meaningful for the family, even after the child's death. We describe how care givers together with the Make-a-Wish NL Foundation select children and work to make their wish come true. We address the importance of this 'ritual' by presenting comments from children who have been granted such a wish.

[terminal illness, children, last wish, rite of passage]

During the course of their illness, severely ill children and their families, as well as care givers, experience on-going stress. This paper reflects on granting these children a last wish as an authentic palliative moment – for patients and their families. In the Netherlands, these wishes are granted by volunteers like those who work for the Make-a-Wish NL Foundation (MaW NL). The granting of a wish can be viewed as an ante-mortem ritual and a rite of passage. We consider the phases of a child's disease and ensuing death using rite of passage concepts put forward by Van Gennep (1960).

A story from ancient Egypt

In many cultures the death of a child passes without any ritual. But the opposite may happen as well. Since ancient times, people also have treated dying children in a special way. The Egyptian section of the Dutch National Museum of Antiquities in Leiden, presents us with a picture of the life and death of young people in ancient Egypt. It is a fascinating display of children's toys painted in black and white, such as wooden puppets, a boat and small animals – artefacts with a high level of craftsmanship. “Grave gifts for a child” the sign says. Were the toys a gift when the child was lying on its final sickbed? Or perhaps they were meant to pay the ferryman further up the river Nile for the trip to another world? Perhaps the toys were intended for play in the afterlife? Today, we do not give children toys at their grave but we try to grant them a final wish before they die.

Currently attention to a seriously ill child is more focused on the here-and-now. The river of death and afterlife are now considered as thanatologic elements of old narratives (Clark 1989). Hope for the future is demythologized: the next birthday, new clothes, or a new school. For children with cancer, there is hope that their next chemotherapy will be effective. But what does ‘hope’ mean today for a child with a life-threatening illness?

How wishes come true

The organization

In the Netherlands, the MaW NL and its home foundation, the Make-a-Wish Foundation International, De Opkikker (Booster Foundation), and the Ronald McDonald houses are all actively granting wishes for seriously ill children.

We focus on the MaW NL, whose mission is the performance of the dearest wish of children aged between three and eighteen years with a life threatening disease to create an experience of hope, power and happiness. The children, who are suffering from a serious, life-threatening or end-stage illness, or in a broader definition – experience a severe and sudden twist in the course of their disease – are candidates for a wish.

A small office with a paid staff supervises selected volunteers who explore the wishes of the sick children. The children who want a wish are generally presented to the MaW NL office secretariat by family members or hospital paramedical workers. Minimal data about disease or handicap, treatment and hospital are collected and put in an electronic data file and form. The Board has a Medical Selection Committee (volunteer physicians) who screen the children using a standard list of diseases (the Medical Guidelines). One of the volunteer physicians receives the electronic form confirmed by the treatment centre, and he/she consults with the child's attending physician. The MaW NL physician makes a recommendation for the Foundation to grant or not to grant the wish.

The children

Two examples of two specific children with a life-threatening illness illustrate the selection process.

Sandra has an inherited disease called neurofibromatosis. It presents with small weak brownish tumours in the skin that are harmless, but disfiguring. However, when the tumours are in the brain they can grow and interfere with brain functions. So, although the tumours are benign as the lesions grow, they can develop into a serious condition. After Sandra's case was evaluated by the MaW NL Medical Committee, it was agreed that children with the diagnosis 'brain tumour' would get their wish immediately.

Henk was born with a malformation of the heart: his blood partly bypassed oxygenation in his lungs. His face and hands looked purple and he lacked energy. Henk needed surgery, but this was only possible after his body had matured. Since Henk was under three, he was not a candidate for a wish according to the MaW NL Guidelines. If Henk would still live after the age of three, he could be operated on and his chances for survival would be excellent.

The type of disease and the chances of survival are important considerations for a wish, but in many cases the door stays ajar even after the initial decision 'not eligible'. Once approved by the Medical Committee for a wish, the MaW NL volunteers visit the home of the child and draw up an inventory of the child's wish and make a scenario for granting the wish. The volunteers are committed to help solve all the difficulties for granting the wish by using their network, which is generally in the geographic area of the child's home, but sometimes also abroad. Volunteers – mostly with a (para)medical or teaching background – are trained to alleviate a child's pain or to remove hindrances for handicapped children to have their wish fulfilled. An example may make this clearer.

John who is four years old asked a volunteer: "Can I make music in a drum band?" "Why do you want to do that?" asked the volunteer. "Eh, because my uncle has that hobby. I like the music so much, and the nice uniforms!" After a positive screening by the Medical Committee, the volunteers of the region screened John's physical ability and energy to walk and participate in his wish all day long. Then a drum band was selected in his hometown. It was decided that for John, the band should play indoors, so a big sports arena was hired. The drum band spontaneously offered to make a uniform for John; his clothing size was secretly given to the band by John's parents. The belts of a small drum were adjusted to John's body size. John and his family are transported in a stretch limousine. A fun restaurant was selected for his pancake dinner after the drumming. A list of guests, including John's relatives and school friends were informed and invitations sent out. A photographer was engaged to take pictures and shoot a video. The timing of the event was crucial to ensure John would enjoy himself. Later, in a family reunion the day

was discussed and evaluated. The MaW NL panel afterwards sent out a summary of the day with text and pictures to all participants.

Initial reflection on John's major theatre performance shows a 'yes to life', and a denial of the sorrow of sickness and forthcoming death for John's extended family. Death in this context is not only a bodily but also a spiritual end. With this ritual, having a wish granted, the life of John was celebrated before ending. To recollect the meaning of this ritual the pictures and soundtrack could help John's family and friends to synchronize their feelings and focus on John.

Nathalie had an unusual request for her dearest wish. "Nathalie do you really want to make a tour of a pig stall?" asked the volunteer, after her parents had explained the eight-year-old's seriously immune-compromised state. "My friends always tell nice stories about the pigs, especially the small red ones! They can go there very often after school." The volunteers thought this plan could not work as infection could lurk in every corner of a pigsty. After doing some research, a farmer was found who was willing to open his breeding station 'laboratory' with very young piglets in plastic containers and a sterile environment. The whole group accompanying Nathalie was dressed in light blue outfits as if in surgery. In her chair nicely decorated with paper flowers she asked lively, "May I hold one of the funny piglets, here in my lap?" and she opened her arms wide to hold them all. "How cute they are! This tail is curled and cannot be straightened just like my life, daddy," she philosophized. The farmer's gloved hand gently touched Natalie's head as he took the piglets back and told the group: "I did not know these screaming pigs had the power to help the sick child, I was perplexed to encounter this" (Bjornsen 2000). How she and her kin enjoyed the event that day!

Again, Nathalie enjoyed her wish, a unique experience of happiness surrounded by adored animals and beloved relatives, which simulated her life full of authenticity. Although this day was a step nearer to her possible death, it was unconsciously ignored.

Many children do not live long after receiving their wish. Recognizing and addressing mourning is a special skill for volunteers of MaW NL as many children die shortly after the day of their wish (Hunter 2007). Much of the volunteers' actual work is improvisation. A trip with a seriously sick, sometimes (mentally/physically) handicapped child cannot be successfully undertaken without adequate preparation, experience and wisdom. The following examples may clarify this.

Pedro is a boy with a life-threatening asthma. "Can I make a trip to the snow in the mountains with my folks?" he asked, gasping for air. Volunteers made all preparations after he was cleared by the Medical Selection Committee and the trip went well. "We are having great fun," he yelled, to his family, curving his skis in the powder snow as a skilled sportsman. "Yes these sportive days and togetherness is his dearest wish and gives him more energy to live," said his smiling parents. That night, however, an asthmatic attack in the cabin was fatal. "We could not help," the accompanying volunteer said, "the

oxygen supply was not effective anymore and there was no transportation due to heavy snowfall.”

Back home the volunteers and family were professionally supported to address their grief of the anticipated but yet untimely death. In this case, the ritual of the wish accentuated the worth of Pedro’s life in his social context and simultaneously gave the survivors a valuable memory.

Disease as a process

A range of diseases is presented to MaW NL including severe epilepsy, Rett syndrome, cystic fibrosis, Duchenne muscle dystrophy, Langerhans’ histiocytosis and disorders in need of organ transplantation. Children with a life-threatening illness pay multiple visits to doctors, both in hospital and outpatient settings; blood samples are taken and internal organs are imaged. The moment of diagnosis, after long days or weeks of waiting, is followed by a plethora of therapeutic procedures. But the process of being treated for a life-threatening disease also has ritual characteristics.

We could consider a serious or life-threatening illness as an intense and threatening period that marks the transition from a healthy state to sickness and from terminal sickness to death. In this way, a serious illness can be placed in line with birth, marriage, puberty and menopause as biological transitions in a life. In all societies, rituals and celebrations make these transitions special. Medical treatment for childhood life-threatening diseases can be compared to passing a threshold. Can the fulfilling of a wish also be regarded as a threshold with a ritual dimension?

Rite of passage

According to Van Gennep (1960), rites of passage have three phases: separation, transition, and re-incorporation or respectively preliminal, liminal and postliminal. We will use Van Gennep’s phases to examine the rituals marking the phases between childhood life-threatening sickness and death, and extend this to include the newer insight of palliative care with a child’s wish.

In the first, preliminal phase, people withdraw from their current status and prepare to move to another ‘place’. Initially a healthy child is living a normal life with daily activities like eating, drinking, going to bed, attending school, playing with friends, gossiping, etc. When the child has a life-threatening or severe illness, there is often a detachment or ‘cutting away’ from the former self, which is signified in symbolic actions, for example, having repetitive blood tests, removing bandages from wounds, infusions of chemotherapy, hair loss due to drugs, operations, etc. Thus, the child changes from a healthy child into a child with an illness.

The second or liminal phase is the period between two states, during which one has left one state, but has not yet entered or joined the next. When the clinical signs of

disease appear in a child and *separate* him/her from his/her group, the social 'status' of being a 'pupil of class A3' is destroyed. The parent or guardian notices expressions, gestures and sounds that suggest pain. Food and drinks are refused and self-care is neglected. Special wishes can be hugging with comforting dolls, reading from books or singing lullabies. When all the criteria for disease are present and a child's colour fades, his energy slows and he stays in bed, the child has entered the 'territory' between health and sickness.

During the sickness, the child drops out of school and club activities, has periods of being bedridden, and endures multiple medical interventions. As the disease progresses, the child's circle of friends and family gets smaller, talk turns to discussions of nurses and doctors, visits to hospitals and treatment programs are becoming normal events. In between endless phone calls, sms messages, and communication with Facebook pals in the web of relationships are now part of daily routine together with quiet game playing, or dozing on the sofa. The transfer from the cosy bedroom at home to the clean and technical environment of a hospital ward may be necessary. When treatment for cure is no longer possible, the child has reached the end-stage disease.

In the third phase (re-aggregation, re-incorporation, or postliminal) the passage has been completed, the child has assumed a 'new' identity, and re-enters society with a new status. Now, in our context two possibilities exist theoretically. One is death, and the other is the unexpected surprise: continuation of life and revitalisation of the body, into a reasonably normal state or with a bearable chronic disease state – *re-integration* is possible (Garrett 1997). When children survive their illness, they have the status of a healed child, who can show the used boxes of pills, postcards and presents received in the hospital. They must try to make a restart into society with the family at home, school, clubs, etc. Physically the children can show the effects of the traumatic hospital stays and treatments like a bald head, scars or infusion needle sites, but they might also experience mental consequences like nightmares, loss of concentration or even dissociative symptoms (Nijenhuis et al. 2002). However, some children may bear the stigma of having been 'deathly ill' from cancer, severe asthma, a progressive metabolic storage disease, etc. Successful treatment procedures and 'coming to life again' means a stable or chronic disease with 'only' routine medical check-ups for the foreseeable future.

In the end stage of a disease, the will to (re)find the ultimate worth of life is a personal quest for the child and its kin. The process of being sick and the effort to overcome sickness is an experience with multiple encounters with many people (doctors, nurses, etc.) and the personal attitude one takes toward unavoidable suffering opens a way for a child to find meaning of life. Ceremonies like first using an adapted red wheelchair outdoors, changing to new clothes after wearing hospital pyjamas are all relevant.

A last wish as a peak life-experience may mark not only the recognition of overcoming death and a defeat, but also a positive turn for the better or the mental support to fight, a sense of identity or confirmation of bonding (Bjornsen 2000, Bluebond-Langner et al. 2007). Two requests are presented that reflect a wish related to identity and bonding as well as a ceremonial or ritual activity. Ricardo asks: "Is it possible

to say goodbye to my old granny in my faraway homeland?” and “Can Achmed say prayers with his father in Mecca during the pilgrimage (Id-ul-Hadj)?” Some children’s wishes seem to be a positive turn for the better or a personal quest. Kevin would like to “drive a fast fire-engine with loud sirens and flashing red lights” and Sara would like to “sing with a young Star girls’ music band, wearing full makeup and a glittering dress and please take some nice photographs of the set.” The connected group enjoys carefree fun, while death is momentarily put on hold, edged out; as the biblical quotation goes: “Death, where is thy victory?” (1 Corinthians 15:55).

Conclusion

In the child-friendly Leiden Museum, mentioned above, one can stick together a paper model of a small boat, with which a child was supposed to make the last trip and cross over to the other world. The rites of passage in books and museums invite discussion among parents, educators and doctors about the threat of death, and the comforting aspects of good, palliative care.

We have shown how a child with a severe or life-threatening illness can be seen to be passing through a rite of passage, thinking of a wish, having the wish granted and finally, receiving and re-visiting remembrances of the wish day. We have used Van Gennep’s three phases of rites of passage to trace the child’s wish.

Granting a wish is an unusual ritual in a society where funerals are celebrated after a person has died. Tokens of affection and gratitude are literally post-mortem, too late. Loving words are spoken to a dead body in a coffin. The wish fulfilling ritual described here makes it possible for the dying person and those who stay behind to express emotions to one another before the final departure. Granting a wish makes those participating in the event forget death for a moment; it becomes a celebration of life in the face of death.

Note

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All names of sick children and their families in this text are fictive.

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