DRAWING TO AID RECOVERY AND SURVIVAL

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This paper considers the role of drawn visual communication materials and their effectiveness as a means of obtaining informed consent. The researchers used practice based ‘action research’ as a means of working with clinicians at the Liver Transplant Unit, Birmingham Children’s Hospital, UK, in the preparation of materials (in this case picture storybooks) leading to medical surgery. The researchers’ approach was designed to match the needs of the hospital and the nature of the investigation.

Keywords: drawing as non-verbal communication, medical problem solving, practice based action research, cognition, and theory.
INTRODUCTION

The physiological recovery of young children from invasive surgery at Birmingham Children’s Hospital’s (BCH) was of particular concern to its behavioural physiologists and play therapists. Professor Kelly identified the need within the Liver Unit to improve the quality of life in young transplant patients. Her team looked to creative approaches and solutions.

After initial consultation with the clinical team, designers Mario Minichiello and Liz Anelli decided that ‘action research’ methodology would be best to continuously inform the development of these creative materials.

IDENTIFYING THE PROBLEM:

Clinical data was gathered throughout the research, design and implementation process by BCH’s medical team. Due to the hospital’s ethical and data-protection policies we are not however able to publish the information within this paper. The components that relate to developing the research project and the resulting children’s books are reported, but without reference to individuals.

Research conducted by this team identified the need to find new ways of communicating with children in the target age group (5 to 8 years of age) in order to prepare them for surgery and to ensure improvements in the recovery process. Visual communication, defined as ‘communication that relies on vision’ (Farlex 2012), was seen as the key method.

In collaboration with play therapists Liz Anelli wrote and illustrated narratives for two books to address these main patient age groups. A colouring book (with very few words) was designed for the youngest (new readers) group. Mario Minichiello designed and Liz Anelli illustrated a storybook for the older group with more detailed and complex narratives, which also had to acknowledge the different cultural backgrounds of the children. As Penni Cotton observes in the cultural role of children's books in Europe: “The most important aim has to be to communicate the similarities and differences between cultures through carefully selected visual narratives ... “

The books would have the appearance of conventional children’s books but the contents and design developed to:

1. Obtain informed consent from children facing liver transplant surgery (within established ethical measures developed by the hospital),
2. Understand from the child’s perspective what were the main causes of concern in the pre-operative and post-operative process and address those issues.
RESEARCH METHODOLOGY

The information gained from the application of ‘action research’ methods guided the development of the book design process by creating a narrative that more accurately assessed and then addressed the children’s key concerns.

The Research Method plan was cyclical:

Stage 1: Defining the problem: Initial planning used information from the behavioural play specialists and leading ward sister. The aim was to reduce the chance of shock or other forms of post-operative trauma by addressing key questions that arose from patient concern – these were broadly:

- Why am I here?
- Why do people here dress in that way?
- What will happen to me?
- What do the machines do?
- What happens when I am asleep in the operation?
- Will I be safe?
- When will I be better and when can I go home?

Stage 2: Action plan: Considering different approaches of addressing these questions or indicative areas of concerns. This included looking at creating games and perhaps specific toys that followed the child through their operation. Action research, as described by McNiff, ‘is a form of inquiry that enables practitioners in every profession to investigate and critically evaluate their work by producing accounts of their practice’ (McNiff 2011).

The first stage was to develop storyboards as a generic part of any of these possible outcomes. The storyboard depicted different stages in the surgery procedure. They were used in the play schemes to set up scenarios and to prompt the child’s interaction and evaluation through play.

Stage 3: Taking action after reflection and further planning. This lead to a number of refinements: written texts, picture book storyboard development and explorations into drawings of the characters (character development).

Stage 4: Evaluating actions taken: The children and family members worked with what is referred to as in industry practice as a pencil line drawn ‘mock’ or ‘dummy book’ which was developed from the feedback from initial storyboards.

Stage 5: Specifying learning contents: Purpose drove the initial visual hypothesis including the draft story. Context was further refined and developed through consulting, planning and action, repeating the cycle and continually refining the information. The
final outcomes enabled children to understand and be informed as to the nature of their condition and the surgical processes. This enabled them to consent to the operations and in each case this consensual agreement aided their immediate recovery and enabled a better level of planning for the medium and long term management of their condition.

DEFINING THE PROBLEM AND CONSIDERING COURSES OF ACTION.

Drawing was used as a means of conceptualising and visualising throughout the project - in meetings, in play therapy sessions as well as for the end outcomes. The drawing process enabled child patients to think creatively about their questions and better express or debate them through the drawing process with clinical staff. This introduced a new way of thinking and as Ken Robinson suggests ‘new ways of thinking can transform us’ (Robinson 2001). To understand the data the team had to design a process of engagement around the key questions and the children’s emerging drawn images.

Through their own drawings they were also able to share their concerns with members of their family and the other children in the Liver Unit. This enabled them to be part of a group and not to feel isolated or too home sick. As Berger observes ‘the static image of a drawing, or painting is the result of the opposition of two dynamic processes.'
Disappearances opposed by assemblage’ (Berger 2007). Through drawing the children were able to ‘reassemble’ their homes and the things they missed.

Forms of verbal protocol analysis were used to identify significant issues and behaviours that might become a concern. This was in order to use the ‘verbalisations of thoughts’ that children made during the deep levels of concentration occurring in and resulting from the drawing process.

Ericsson and Simon argued that the closest connection between thinking and verbal reports is found when subjects verbalise thoughts generated during task completion. When subjects are asked to think aloud, some of their verbalisations seem to correspond to merely vocalizing ‘inner speech’. ‘The verbal probe may be constructed to induce the subjects to generate information about the hypotheses under consideration’ Ericsson and Simon (1993), which would otherwise have remained inaudible. ‘Non-verbal thoughts can also be often given verbal expression by brief labels and referents’ (Renkl 1997).

This is not intended as a detailed description of the child’s cognitive processes but it does help to elucidate some of the drawn information. The extent of the verbal and drawn description of an issue reveals how deeply embedded or troubling it might be to a child.

SELECTING A COURSE OF ACTION:

The illustration brief which arose from this process, therefore addressed the following questions:

- Why am I here? How to visualise the journey from illness into recovery.
- Why do people here dress in that way? Remediating the appearance of things and people, in particular the human face when masked.
- What will happen to me? How to visualise the journey to recovery in detail, with positives.
- What do the machines do? RemEDIATE machines and processes.
- What happens when I am asleep in the operation? Detailed explanations that have positive and caring overtones.
- Will I be safe? What did the child regard as safe?
- When will I be better and can go home? How to visualise going home and normality – not stigmatised being as different in the society of other children.

This information helped to develop the brief, which was to develop two children’s books for different age groups to take the ‘reader’ through the detailed journey to recovery. The written and visual language and design of the books could not be ambiguous or
inconsistent. There was a clear aim not to ‘dumb down’ either the process or concerns of the child. The approach taken was that the narratives would be designed to prepare the child for the realities of clinical procedure. However care would be taken not to overly instruct – the aim was to create an inspirational children’s book adventure, not a medical manual.

BCH is an international hospital – English not always being the first language used. This was one of the challenges we faced but it also made picture storybooks with ‘their cooperative balance of text and image’, a natural solution. ‘Picture books are a significant means by which we integrate young children into the ideology of our culture’ (Nodelman Reimer 2002).

The visualised storyboards and stories became cognitive models, articulating through drawing a form of learning about a complex process that reassured the child and allayed their fears.

Through play therapy sessions the children raised a number of issues. For example, any masking of the face is immediately problematized by the relationship the child has in reading emotional information from facial expression.

In reflecting on the concepts behind children’s book illustration and publishing, Minichiello/Anelli cites Piaget: ‘As babies develop they respond to an increasingly sophisticated differentiation of the pattern of a face. They are progressively able to discriminate between the spatial order and shapes of facial features. This process is reflected in early years drawing development. Faces are vital to young children and they habitually draw them larger in proportion to bodies’ (Piaget 2001).

FIG 2: MINICHIELLO, C. ‘DADDY’. (DRAWING PENCIL)
Illustrations had to address this within the written/read textual narratives, the sequencing in the layout design and in drawing details. Even where the inclusion of a surgery mask was necessary it was possible to convey thinking and emotion by how eyes were depicted. The physical entity of a book enable time to be spent with each image, to absorb the masked face and reposition it in the mind as an element in the journey to recovery.

Another key concern was the depiction of home, familiar environments and objects both in the pages of the books and in the drawings surrounding the children in their hospital spaces.

This thinking was based on the best practices, As Thornton and Brunton observe at the Reggio Emilia centre in Italy: ‘the quality of the environment in the infant- toddler centres and preschools is an important value of the Reggio approach. It plays an active role in how children play and learn’...(Thornton Brunton 2007). Placing these elements carefully within the storyboard enhanced the sense that each child was getting closer to going back home.

Furthermore the fear of being abandoned, being left, lost or in a strange place arose from the testing of the storyboard images. This fear is not helpful in the recovery process and can be a difficult issue to address. The repetitive re-telling of the stories became key in re-casting the operation theatre and recovery intensive care room as a magical space of healing – ‘reality adjustment’ as the last phase of a child's "magical thinking". Piaget contends that this is the beginning of maturation (Pearce 1974).

Habitual usage gave another reason for picture books to be a viable solution for benefiting informed consent. Story-time within families often follows set patterns with the same books being selected as part of a ritual. This meant that the Liver Books would become inculcated into the families’ shared knowledge, of vital importance when it is considered that a liver operation is by its nature an emergency procedure that depends on the death of another patient and a rapid response by medical staff and receiving family alike.

STUDYING THE CONSEQUENCES OF ACTIONS TAKEN

The child feared being removed from home and the loss of their emotional connection to objects, situations and people but most of all to a detailed memory of themselves and their bodies. This presented an interesting dichotomy between how they remembered and drew themselves and how the operation changed their appearance.
The cognitive challenge was to present the narrative journey as a means of considering the relationship between being ‘unwell’ and being cared for and supported, to being ‘back to their normal selves’ as the person that they had originally visualised.

Drawing is one of the earliest forms of self-expression that children develop in order to make sense of the world and their place in it. This is well documented in ‘early years’ development research, which supports the use of picture storybooks to encourage and consolidate learning. Pictures plant the seeds of learning and encourage children to think creatively and positively about their future. Drawing their own pictures allows children to explore the ideas they have encountered, including difficult issues and themes.

The aim of engaging with the concerns of the children through their own drawn images enabled researchers to better modal and develop the people drawn in each of the books – and to ensure that the main character design provided an empathic modal through which the children could begin to consider the differences between reality (how things are) and the imagined worlds (how they might be), ‘pictures and artefacts around the setting to act as starting points for children’s creative expression’ (Thorton Brunston 2007).

It is here the questions about the body had to be addressed. The process of liver transplantation is extremely physically invasive. This reality became more clearly understood through the storyboard and raised many concerns among the children and their parents (some parents expressed the view that this aspect might be best not discussed and visualised so openly). This would have simply compounded the problems being encountered in postoperative recovery.

The results of this thinking and data suggested that the images needed to be recast into a positive narrative with an achievable outcome that the child would believe. Key motivational factors are reiterated through the design of the books. These centre on the character of Anita and her journey through the liver transplant surgical processes.

As a consequence of their operations the children have to encounter new devices that become part of their bodies. These devices change their bodily functions and interfere with intimate day-to-day interactions such as handholding, drinking fluids and removing fluids from the body. Therefore the focus of each illustration increasingly became concerned with ways to mitigate the potential for shock or the unknown.
In the ‘New Liver Colouring Book’ the child colours in the line drawings and explores what is going to happen to him both through the Imagery and with the psychologist through directed play.
The storybook for the older child as part of the preparation to gain the child’s informed consent, read as any other picture storybook.
As part of the process, research into contemporary children’s books was undertaken to compare best practice and this revealed significant areas that might aid the team in explaining difficult concepts.

Many modern illustrators and writers have used key words repetition (the early Ladybird Book school reading schemes or the more palatable Doctor Zeus ‘Cat in the Hat’ series), word association and phonics. Integrating words and images builds visual comprehension and reading skills. Words and pictures in sequences animate meaning and prompt memory. As Stefania Tondo states in her thesis, ‘A wonderland of pictures of Alice from Italy’, this is in effect ‘a desire to translate the surrounding world into a more pleasurable language. It is also a desire to escape from the kind of book without pictures and conversations that young children might be threatened by…’(Tondo Harding Pinsent 2008).

In creating different imaginary situations the play therapy researchers were able to test the different approaches of some of these other children’s books, juxtaposing them to emerging behaviour patterns. Some of these behaviours are long recognised as a part of the child’s development and these are reflected in the ‘cautionary tale’. Cautionary tales (traditional folk tales and the stories of Grimm, Anderson, Belloc etc.) have been a long established means of instructing children into the adult world and dealing with difficult issues. Not Now Bernard by David McKee proves to be a useful reference point. McKee’s book deals with a child’s anger, the monster that fear can develop into. This is a prime example of a narrative that is intended as much for the parent as it is for child. Here an ignored (perhaps unloved) child becomes the monster.

The ability to read relevance into the relationship between text and image leads to the leap of reader interaction, expectation demanding and thus stimulating higher cognitive awareness. Creative thinking allows the child to imagine a better outcome and understand their role in providing their consent. Creativity is ‘the ability to see problems in new ways’, ‘to see things from a new perspective’, and ‘the knack of looking for answers in unexpected places’. The dictionary defines illumination as ‘throwing light on a subject in order to see it better’. Words used for clarity of thought: insight, foresight, hindsight, and clear-sightedness all contain visual reference. (Edwards 1986)

This means that the child can ‘ask’ and this asking can emerge through play and through the child’s own drawings. Child psychology says much about the primacy of drawing and ‘visual literacy’ but how can this be developed and used to resolve a particular medical challenge and improve recovery from major surgical procedures? What approaches can be developed through medical and illustrative partnerships to create new ways to compensate for the lack of verbal expression in young children? How can ‘creativity’ expressed through drawing be used to communicate to young children facing major surgery ways that allow them to visualise a better future?
The consequences of these actions essentially addressed the underlying concern of how a drawn narrative can help a child (and their family) face the reality of a potentially life-threatening situation. How can they 'envision' their place in the world when their place in it is not assured? When their survival is contingent on the care and action of others? It highlighted that when children have internalised and accepted this, they can consent to be helped through this difficult journey, and that they can in length return to normal lives. By continuous exposure through a supportive team of people, difficult ideas can come to be regarded as a normal part of dealing with illness and an aid to their recovery.

IDENTIFYING THE FINDINGS AND NEW KNOWLEDGE

Actions taken had addressed questions raised in children’s study groups, further assessed through the use of the picture books by the play therapists. Studies had disclosed how operational equipment and instruments had become fearful objects. The approach taken in the books’ design and illustration therefore avoided misleading the child about the nature of the procedures involved. By not taking a comical or cartoonist approach the researchers were better able to represent the true nature of surgery.

The Liver Unit had presented some interesting challenges in its highly specialised care, communicating with twenty-four different specialists within the Hospital. Established parameters were that the language of texts needed to be medically accurate but at the same time easily understood, thus paving the way for imagery to take prime place.

The rationale was to achieve three things: firstly, to address informed consent; secondly, to prepare the child (and family) for the realities of surgery and finally - to address the difficulties of post-operative reaction to the trauma of surgery and living with an on-going condition. Hospital-based play therapy around the guided use and then home ownership of the set of books were key to all three.

The design and illustration of both books reflected the key aspects of other contemporary illustrated books. These particularly rely on drawing for their impact and the fact that handmade images provide encouragement for children to engage in developing narratives through their own drawings made about the books they read. Even a brief look at any primary school wall reveals this process. Drawings have recurring themes such as loved objects of comfort and affection, soft toys, pets, a depiction of home, a clear sunny sky.

Drawing and drawn books enable children to encounter difficult aspects of our world within the safety of their imagination and the small focus of a hand-held book, on a par with other familiar toys. Examples of this can also be found in the canon of contemporary children’s books such as in John Birmingham’s book, Granpa, which
deals with the death of a loved one. It has an unsentimental realism that gets to the heart of the matter.

Engaging with the action research methods resulted in turning very detailed and technical medical information into a fully mapped out storyboard, developing key characters and a detailed picture/word story. Throughout three months of work content was controlled by a series of meetings and dialogues concerning portrayal of every aspect. As the creative team, we sensed that our visualisation methods during these sessions prompted greater and more enthusiastic support across the diverse medical teams. Both sides of the team (medical and creative) appreciated the dexterity of the drawing language and the deep power of a book author/illustrator’s imagination to enable problems to be overcome quickly and with good humour. All aspects were thoroughly tested by play therapists for simplicity and ease of use. Even the shape and size of the books were altered to being more easily portable, part of the families’ essential ‘going into hospitable’ kit.

The advantage of using illustration, the drawn image, allowed what could have been horrific, through the graphic reality of photography, to become acceptable. The design of ‘difficult moments’ was particularly carefully thought through with all the team at the hospital.

Fig 5 demonstrates the flexibility of illustration allowed us to show not only what was happening but also what individual characters were thinking. Compositions could be selective and softened within the language of the illustrator.

The world of the hospital was made a happy and bright place, positive outcomes assured and people reassured. The books’ textual and image dialogues combined to encourage leading questions from the reader enabling the hospital staff to discuss all issues, no problem too big or small, a major part in ensuring recovery.

This was an impact practice-based research project that highlighted the use and power of the drawn image to work within the imagination and project the child’s thoughts towards a better future. Verbal feedback from the hospital verified significant improvements in the children’s reactions and abilities to accept the initial impact on their appearance of liver transplant. This resulted in better family experience and consequently more positive recoveries. To use what has now become a cliché, in this instance ‘a picture did serve to speak a thousand words’ (Barnard 1927)
This is called a butterfly needle.

The Doctor puts a needle in Anita's hand. It scratches a bit but the nurse makes it better with a bandage and the promise of some tea.

REFERENCES


