Narrative health communication: Exploring how medical comics can be designed to support children with serious illness

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Abstract

Information can empower and create understanding among patients, although some topics can be difficult to talk about. For instance, it can be difficult for parents to talk with their seriously ill child and her or his siblings about the illness and its treatment. The purpose of this paper is to examine contemporary medical comics as a form of narrative health communication and to provide designers with some considerations on how to use visual and written elements for supporting favorable communication between children with serious illness and their families and other caregivers. A content analysis of three medical comics was conducted to identify and compare how narrative communication has been applied and relates to a set of narrative health communication benefits. In addition, a scoping literature review was carried out to identify how narrative communication can be optimized for application in medical comics. The analysis showed that the medical comics for children ended on a positive note, even when describing very emotional and existential issues, while the comic for adults described more realistic situations. Furthermore, the analysis revealed that stories with human characters might be better at creating a feeling of companionship compared to stories with fictive characters, as comics that present narratives about patients can offer companionship to readers that are patients themselves. Based on the literature review, the moderators of character identification and sequence coherence have been investigated and discussed from a health communication perspective.

Keywords: Narrative health communication, medical comics, information design, children, parents

1. Introduction

Information can empower, create understanding and liberate humans, although some topics can be difficult to discuss and make sense of. Especially presenting information and talking about serious illness when it involves children is hard. Parents often want to shield their child from undesirable information about the disease, believing they are doing the child a favor by not upsetting them further. However, some studies show that most children over eight years want to be informed about their disease and its treatment, such as prognosis, benefits, side-effects and risks (Ellis & Leventhal, 1993; Last & van Veldhuizen, 1996). Not knowing what

will or might happen can make the child feel anxious, lose trust in her or his parents and create a feeling of loss of control (Beale et al., 2005). Caldwell (2012, p. 2) suggests that comics can be a good provider of information and defines comics to be a "form of communication written in a visual language". In line with this definition, we here understand comics to be a form of communication in itself, in addition to being a medium of communication. Moreover, focusing specifically on health information, comics can "have many advantages over patient information leaflets, particularly in the way in which they can offer 'companionship', helping patients to address fears and negative feelings" (McNicol, 2014, p.49). The feeling of companionship that is created by reading about other people's experiences with the same illness can be comforting for patients (Williams, 2012). In this paper, "comics" refer to still images put together side by side in a sequential order to tell a story, not animations of any kind. The purpose of this paper is to examine contemporary medical comics as a form of narrative health communication and to provide designers with some considerations on how to use visual and written elements for supporting favorable communication between children with serious illness and their families and other caregivers. The most common type of cancer among children in Norway is leukemia (Oslo Universitetssykehus, 2016). This paper takes narrative communication through comics for children with leukemia and their parents as an example.

2. Background

2.1 Comics

Comics is beginning to become applicable in patient care and education (Green & Myers, 2010). Examples can be found in both children's (e.g. Chilman-Blair & Taddeo, 2009) and adults' (e.g. Fies, 2006) comics. For medical comics, there exists a specific sub-genre of adult comics called "graphic pathographies" (Green & Myers, 2010). These are graphic biographies focusing on a person's illness and related experiences. *Medikidz*, a series of medical comics to explain health information to children who are sick, covers difficult topics such as kidney transplants, multiple sclerosis and leukemia (Medikidz, 2017). For adults, there exists websites such as *graphicmedicine.org* ("Why Graphic Medicine", 2018), offering reviews and links to medical comics, such as "Mom's cancer" (Fies, 2006).

2.2 Why use comics as a source of health information?

Comics can offer powerful images and metaphors to explain experiences, terminology and medical science in a plain manner for all family members to understand (McNicol, 2014; Green & Myers, 2010). Furthermore, different viewpoints can be presented in the comic, offering insights into the struggles of i.a. the patient, family members, health professionals and friends (McNicol, 2017). According to Caldwell (2012, p.5): "The majority of studies that report data tend to be positive about the use of comics for knowledge transfer", indicating that comics may be both an efficient and meaningful way of providing and receiving information as well for fostering reflection. Furthermore, patients may relate to and feel less isolated by reading about other patients' experiences (Williams, 2012). Comics prove especially useful to people with low reading abilities (Yang, 2008). This indicates that children may especially benefit from them.

2.3 Narrative communication

Comics make use of narratives. We follow the definition of Hinyard and Kreuter (2007, p. 778) stating that: "A narrative is any cohesive and coherent story with an identifiable

beginning, middle, and end that provides information about scene, characters, and conflict; raises unanswered questions or unresolved conflict; and provides resolution". Focusing on health communication, Hinyard and Kreuter (2007) found evidence suggesting that narrative communication may be perceived by audiences as more personal, realistic, believable and memorable compared to non-narrative communication. Currently the dominant paradigm in health communication is statistical evidence, such as probability (Hinyard & Kreuter, 2007). However, in a study review, it was found that 13 out of 19 studies comparing statistical evidence to narrative evidence suggested narrative to be the most persuasive (Baesler & Burgoon, 1994). Kreuter et al. (2007) identified four health-related benefits of narrative communication for cancer patients specifically:

- (1) Overcoming resistance towards receiving cancer related messages and towards following treatment procedures. It is suggested that narrative communication may reduce resistance to these messages, because it is a subtle form of persuasion (Dal Cin, Zanna & Fong, 2004) and may be perceived as less threatening compared to non-narrative forms of communication (Kreuter et al., 2007).
- (2) Facilitating information processing by enhancing/stimulating attention to, comprehension and recall of cancer related information (Kreuter et al., 2007).
- (3) Providing surrogate social connections. This refers to the relationships people form with characters in literature, stories, news etc., and are similar to companionship. According to Kreuter et al. (2007), there are indications that social relationships have a positive impact on people's physical and psychological wellbeing.
- (4) Addressing emotional and existential issues through narratives can help cancer patients deal

with these issues (Kreuter et al, 2007). Cancer is usually experienced as a scary and lifechanging event, and people may face several emotional and existential issues facing it.

According to Kreuter et al. (2007), these benefits can only be realized when the story is "told well". If a story fails to do this, that is lacks a so-called narrative quality, the benefits of narrative communication will decrease or not be realized (Kreuter et al., 2007). Kreuter et al. (2007) describe the following moderators to ensure a story is "told well": sequence (which is dependent on coherence, plot development and theoretical adherence), character (which includes character development, character's eloquence and emotional intensity), structure (which includes suspense and canonical violation), bounded in space and time (which relates to realism, imagery and cultural appropriateness) and production techniques (which relates the technical aspects of the production such as color, cameras etc.). McNicol (2017, p. 20) states "Narrative, characterization and images are key features of comics that may be important when using this medium [comics] for health information purposes". Several other scholars also recommend using comics to provide medical information because of its narrative abilities (McNicol, 2014; Green & Myers, 2010; Williams, 2012).

3. Method

The content and design of three medical comics was analyzed with help of directed qualitative content analysis (Hsieh & Shannon, 2005). The four health-related benefits of narrative communication as identified by Kreuter et al. (2007) were used as initial coding themes. The goal of the content analysis was to identify and compare how benefits of narrative communication are applied in contemporary medical comics. The following medical comics were selected: *What's up with Richard? Medikidz explain Leukemia* (Chilman-Blair & Taddeo, 2009); *Ghosts* (Telgemeier, 2016); and *Mom's Cancer* (Fies, 2006). These comics were chosen because they depict illness, possess narrative quality and have received positive

reviews (Wolf, 2016; "Mom's cancer", n.d.; "What's up with Richard", 2010). Among the chosen comics, two are targeting children and one is targeting adults. It was chosen to analyze both children's medical comics and adults' medical comics in order to understand what separates them and what makes children's comics unique.

A scoping literature review (Robson, 2011) on game design, visual communication and pictograms was conducted to identify how some of the narrative moderators of Kreuter et al. (2007) may be optimized for application in medical comics. Following McNicol's (2017) identification of key features, specific focus was directed to the optimization of the moderators 'character development' and 'sequence coherence'. Character development means to present the user with character information to help them create an understanding of the character. Due to the fact that "character development" is a very broad term, it has been chosen to focus on character identification, a vital part of this moderator. This moderator was chosen because character identification can help the reader perceive the message as more useful and clear, and makes the message more persuasive (Hinyard & Kreuter, 2007). Since empathy can be regarded as a form of character identification, it was chosen to examine how both identification and empathy could be enhanced. Empathy refers to the ability of understanding and acknowledging the validity of other people's emotional reactions and states (Malt, 2009). Sequence coherence means the desired behaviors and decisions of the story are represented comprehensively and clearly. This moderator was chosen because it is needed to create an understandable story.

4. Results

4.1 The application of the four health-related benefits of narrative communication in contemporary medical comics

What's up with Richard? Medikidz explain Leukemia is a comic for children focused on explaining the illness leukemia and the treatment. The comic may help the reader overcome resistance to chemotherapy by explaining the benefits of the treatment and displaying chemotherapy as the "good guys" protecting your body from the dangerous cancer cells. Applying character identification by using metaphors, such as depicting the white blood cells as knights or "defenders", may make it easier for the child to imagine and remember their function, hence facilitating information processing. Medikidz also provides social connections, displaying the character of a child patient, as a kid aspiring to be an actor, and at the end of the story, successfully becoming one and beating the cancer. This is a positive role model for kids, showing someone who accepts his illness, but does not let it shape him. It describes hair loss, which for many patients can be an emotional issue. In this case, it has been portrayed positively, the child patient is not concerned about losing his hair because he can wear wigs and hats, and eventually his hair will grow out again.

Ghosts is a comic for children about two sisters, where one of them is suffering from cystic fibrosis. Treatment procedures are depicted in a positive manner, e.g. the patient participates in the procedure and treats it as an everyday ritual. This may help the reader overcome the resistance towards medical procedures. Information about the illness is told by the healthy child to explain why the family is worried about the sick child. As such, the story provides social connections for both sick children and their siblings. It represents existential issues by having the siblings discuss death, and by projecting death as a new form of being, not something to fear. It also depicts emotional issues, such as the dynamics between the two sisters and their problems communicating with each other.

Mom's cancer is a comic for adults based on real-life events of the writer. It tells the story of when the author's mom was diagnosed with cancer. The comic may help pre-disposed patients stop smoking, by showing the dire consequences. Moreover, it may facilitate understanding about treatment characteristics by telling about cancer procedures in a narrative. Social connections are provided, showing the family of the cancer patient and everyone's individual role in taking care of her. Especially the patient character may provide both social connections and help dealing with emotional issues by showing her harsh cancer treatment and defeating the odds by surviving cancer with a low chance of recovery. Another emotional issue dealt with is the treatment of the patient. Mom is shown as an operation game board, illustrating the feeling of the patient and family losing control, and handing it to a stranger. There is no positive angle in this, but it may help patients and families understand their own feelings and putting them into words.

4.2 Literature review to identify ways to optimize the effect of comics using moderators from narrative communication

4.2.1 Character identification

In comics, human characters are simplified versions of the reality they represent. By simplifying them, the image no longer represents one specific human (like a photograph), but rather a human being in general; an icon. According to McCloud (1994), this makes it easier for the readers to identify with the characters. In an experiment to determine what kind of character design evoked the most empathy (Hytönen, 2015), forty-two people, aged between twenty and thirty years, were shown an image of the characters in Figure 1. Character A presents a human character, character B presents an iconic animal character, and character C presents an abstract character. The respondents were not given any character context beforehand. The iconic animal-like character B in Figure 1, performed best, although the realistic human character A also evoked strong feelings of empathy.

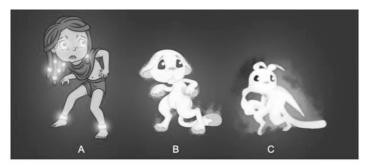


Figure 1: The character designs used in the experiment by Hytönen (2015)

Hytönen (2015) suggests that this may be caused by animals generally being perceived as less threatening than humans, but also because the human character in the experiment was drawn more realistic compared to the animal. Another interesting outcome of the experiment was the fact that the participants seemed to have more empathy for characters expressing emotions clearly. For instance, character B was recognized by the most participants to be scared and scored the highest in empathy. Character aesthetics also plays a part in engaging the user. Van Vugt, Konijn, Hoorn, Keur and Eliéns (2007) found that the more beautiful a character is perceived, the more engaged the observer becomes. Engagement is important for readers to identify with a character (Hinyard & Kreuter, 2007). It has also been suggested that playing

games using a character rooted in your own culture can increase identification with the character (Bachen, Hernández-Ramos, Raphael & Waldron, 2016).

4.2.2 Sequence coherence

In comics, sequence coherence relates to two aspects: Visual coherence and textual coherence. Regarding visual coherence, McCloud (1994) states that action-to-action transitions between panels in comics are most commonly used in Western comics and suggests that this is because it is the most comprehensible of transitions in that it projects information in the most efficient and concise way. Action-to-action transitions depict movements as the subject experiences them. An example of an action-to-action transition is depicted in Figure 2.



Figure 2: Tintin is a typical example of a comic using action-to-action transitions (Hergé, 1971)

A review of studies on health care communication and pictograms, found that five out of six studies concluded that adults understood more when text and pictures were combined compared to text alone (Houts, Daak, Daak & Loscalzo, 2006). Additionally, Houts et al. (2006) found that unless readers understand the correlation between the picture and the text, the picture will have no effect on comprehension, but will rather create confusion. Furthermore, simple drawings combined with text are the most efficient in creating comprehension, compared to detailed drawings and images (Moll, 1986; Readance & Moore, 1981). It has also been found that culture sensitive images positively impact comprehension (Dowse & Ehlers, 2001). According to Skogen (2017) children have problems interpreting abstract symbols. Such symbols should therefore be avoided in comics or tested to verify their readability among children.

Regarding written or textual coherence, Tutty & O'Connor (1999) have suggested guidelines for making a comprehensible patient information leaflet. To avoid confusion: (a) Information should be specific rather than general, (b) Sentences and words should be simple and short, to make the information accessible for all readers, and (c) Sentences should not contain more than two ideas and avoid repetition and contradiction. To achieve more personalized patient communication: (d) The voice in the leaflet should be active ("you have to...") rather than passive ("the patient should...") and (e) familiar language should be used when describing medical terminology. Dyregrov and Raundalen (1996) suggest that adults should regularly verify if the child has understood the information correctly. According to Reinfjell, Diseth and Vikan (2007) children gradually process complicated information, and concrete experiences can help them integrate more complicated information in a shorter amount of time. In other words: children should be given information gradually, and it should correspond to the current stage in their treatment and their experiences. Although not having received much research, one study found that parents gradually informing siblings about the child's illness was a good strategy, allowing the siblings to gradually adapt to the new situation (Maree, Parker, Kaplan & Oosthuizen, 2016).

5. Discussion

The purpose of this paper was to examine contemporary medical comics as a form of narrative health communication and to provide designers with some considerations on how to use visual and written elements for supporting open and honest communication with children who are seriously ill and their family members and other caregivers. To this end, three medical comics were analyzed to identify and compare how narrative communication have been applied to achieve a set of benefits proposed by Kreuter et al. (2007). Moreover, a scoping literature review was conducted to identify how visual and textual elements in medical comics, specifically in the form of character identification and sequence coherence, may contribute to enhance health communication.

The findings from the content analysis of three medical comics show that aspects from narrative communication have been applied differently and to different extents. The most striking finding was the difference between adult and children's comics depicting illness. Both Ghosts and What's up with Richard: Medikidz explain leukemia dealt with emotional issues such as hair loss and death, but ended on a positive note. Their focus was to comfort the readers. In contrast, Mom's Cancer did not always provide a happy ending when discussing emotional issues. Instead of providing comfort for the readers by making a happy ending, the author created realistic situations to which the reader can relate. Dealing with emotional issues while providing happy endings can be seen in connection to children's gradual processing of complicated information. A gradual and careful approach might be preferred by adult family members as well. Designers of children's medical comics should carefully consider the timing of introducing topics and information in correspondence to the stages of children's illness, treatment program and their potential related experiences. Additionally, optimization of the presentation of medical information is important, as not knowing what will happen can cause feelings of anxiousness and loss of control, and children may lose trust in their parents (Beale et al., 2005).

The social connections provided in the comics differed: in the comics for children, the main characters providing social connections were children or adolescents, in the adult comic these characters were adults. The designers' motivation to introduce characters with the same age as the reader is probably to stimulate identification with the main characters. Although there are several ways to enforce character identification, age seems to be a good way to do so, because age limits one's freedom and choices, which creates relatable situations and problems. It was also found that by providing the information through storytelling it could be easier for the readers to remember the information afterwards (Hinyard & Kreuter, 2007). It is important to ensure that a story is told well, as this supports its positive effects (Kreuter et al., 2007).

Furthermore, we found that one comic used fictive figures as main characters that represent blood cells to tell the story, while the other two comics have characters that represent human beings. The stories are thus told from different perspectives, by different personas. Character identification may be stronger when the main characters portray human beings that have the same 'role' e.g. patient or relative, as the reader. These stories might be better at creating a feeling of companionship, as comics that present narratives about patients can offer companionship to readers that are patients themselves (McNicol, 2014; Williams, 2012). Hytönen (2015), showed however that feelings of empathy, or the understanding of other people's emotional reactions and states, is not necessarily strongest in characters that present human beings. The study of van Vugt et al. (2007) suggests that the styling of characters also influences character identification as they found that the more beautiful a character is perceived, the more engaged the observer becomes. Furthermore, if the characters' backgrounds are rooted in the intended readership's culture, the readers may have an easier time identifying with the character (Dowse & Ehlers, 2001). This indicates that the realization of character identification is complex, and further research is needed to obtain a better understanding of what aspects of characters support character identification. Although this paper has argued for the use of comics in a medical context, more empiric studies are needed to further strengthen this argument. A concern regards subjectivity; it is argued that characters designs should be aesthetically pleasing and culture sensitive. This indicates that it may be worthwhile to include representatives of the target group during the design process to evaluate which character supports character identification best. Designs may be verified using prototypes or surveys.

To achieve visual coherence, the images in the comics should be drawn in a simple manner to ensure that they are as comprehensible as possible (Moll, 1986; Readence & Moore, 1981). This suggests that characters, background and objects should be drawn in a plain manner, avoiding too many details. What's up with Richard? Medikidz explain Leukemia (Chilman-Blair & Taddeo, 2009) has very complicated and detailed backgrounds. By using less details readers' comprehension could probably be improved. The panels in the comic should mostly use action-to-action transitions because they are deemed to be the most efficient and concise way to convey information in a comic. Conveying health information efficiently and concisely is considered especially important. By using more action-to-action transitions in Mom's cancer (Fies, 2006), information could be conveyed more efficiently. The situation and context in which the medical comics are being read will be crucial for the children's meaning-making processes with and based on the comics. Moreover, there must be a clear connection between text and imagery, if not the readers may feel confused. For comics specifically, this means speech bubbles should be clearly connected to the speaker. Striving for efficient and concise health communication, the images used in a medical comic should also be culture sensitive to the readers' culture in order to improve their comprehension. According to the afterword in Ghosts (Telgemeier, 2016), the author ensured culture sensitive images depicting cystic fibrosis by using stories from the cystic fibrosis community as sources of inspiration. Abstract symbols should be avoided or tested by children to verify their readability beforehand.

To achieve textual coherence, ensuring comprehensible health information entails it should be specific ("medication should be taken at 12 am and 6 pm") rather than general ("medications should be taken twice a day"). Clarity can be improved by using simple and short sentences and words, as well as ensuring sentences do not contain more than 2 ideas, repetitions and contradictions. Both Ghosts and What's up with Richard: Medikidz explain Leukemia use simple and short sentences and words when explaining cystic fibrosis and leukemia. Mom's cancer uses more difficult words and sentences, as well as contradictions. Active voicing ("you should...") is preferred over passive voicing ("the patient could...") and so is using a familiar language, especially when describing medical terminology (e.g. in What's up with Richard: Medikidz explain leukemia the word "transporters" is used instead of "red blood cells"). For children specifically, information should be given gradually to make it easier to process, and there should be a way for parents to verify whether the child has understood the information correctly and to facilitate for communicative meaning-making processes. This could be done by asking the child directly ("can you repeat what we just talked about?") or encouraging them to make a drawing ("can you make a drawing of one of the things we just talked about?"). By supplying the readers with a simplified summary of the most important information at the end of the story, like Chilman-Blair & Taddeo (2009), comics can give the readers information more gradually.

6. Concluding remarks and further research

Medical comics seem to represent an important and adapted form of narrative health communication for children and their family members and caregivers. Making information accessible and facilitating for common meaning-making can be decisive for how children and their families get to terms with a difficult and vulnerable situation. In this paper we have demonstrated and discussed how narrative communicative elements may contribute to children's health benefits. To gain more acceptance and a wider audience, more research is needed. In conclusion, we point out some suggestions for future research.

A concern is that most of the literature used in the review and the content analysis were produced in the United States. It is difficult to determine whether this has significant impact on the findings or not. American and European comics are deemed to be very similar in structure, meanwhile Eastern comics use more panel transitions and their stories tend to be more slow-paced and less goal oriented compared to western (McCloud, 1994). In future research, sources and comics outside the United States should also be consulted. There is also a lack in studies of comics using children as the target group. We only found one study involving both children and comics, in which teachers were asked about the benefit of using comics to teach children subjects at school (Hutchinson, 1949). However, this study is over 60 years old, making it too old to be applicable to this paper.

Studying different situations and determining the appropriate age to inform children of certain vulnerable aspects of their illness, for instance survival rates, would be beneficial to address for future work in medical comics for children. As mentioned previously, narrative communication can be a persuasive form of information (Hinyard et al., 2007). The question is: when should information be communicated in a persuasive way rather than objective? Is it morally justified to present information persuasively, even if it is in the best interest of the reader, and who can determine what is in the best interest of the reader? These are questions worth considering and exploring. Another interesting topic of research is the possibility of improving communication and understanding between the patient and their family by making them read comics presenting different points of view. This could potentially help them understand each other's experiences and troubles. Lastly, comics are stigmatized for being light hearted, juvenile and simplistic (McNicol, 2017; Green & Myers, 2010; Caldwell, 2012). Therefore, adults may assume comics is not the right medium to use to convey important health information and may not take the information seriously. Examining how to challenge this bias is crucial in making medical comics a source of reliable health information.

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