TITLE: Stories - a novel approach to transfer complex health information to parents: A qualitative study

Keywords: storytelling, narrative, qualitative, knowledge translation, croup

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Abstract

Objective: To identify the beneficial attributes and mechanisms of storytelling through understanding the parental experiences of using a storybook knowledge translation intervention.

Method: An exploratory descriptive design involving 23 parents of children presenting to 2 emergency departments for treatment of croup. Parents received a set of three storybooks, each representing a different severity level of croup (mild, moderate, and severe).

Results: The storybooks were evaluated favourably. Parents were better able to understand the progression and treatment of croup by reading the stories, thus reducing uncertainty and alleviating anxiety about their child's condition. Parents consistently reported four positive outcomes associated with using the storybooks: 1) feeling reassured that they had done the right thing, 2) reduced uncertainty, 3) a normalization of the experience, and 4) feeling empowered.

Conclusion: The 'storybook' presentation of health information was regarded favorably by parents as a learning tool.

Practice Implications: The storybook format is a useful knowledge translation device.

Introduction

Storytelling is one of the oldest forms of communication and is “an intrinsic part of most culture” (Lindesmith & McWeeny, 1998). Prior to the advent of writing, oral storytelling was the only tool available for individuals to share experiences (Abrahamson, 1998). Stories can be powerful motivators of change and can spark action, share knowledge and prepare others for decisions that lie ahead. The use of stories or narratives is not a new concept in healthcare, however, its use in Western medicine has been overshadowed by positivist approaches to the practice of medicine and a reductionist understanding of disease (Charon, 2000), including our increasing reliance on technology. Recently, Houston and colleagues demonstrated that the telling of stories helped to lower blood pressure among adult African Americans with poorly controlled pressures at baseline (Houston et al., 2011). While the literature on the benefits of stories and the telling of stories is growing, the evidence base remains largely anecdotal. There are three general themes explaining the appeal of stories. First, stories appear to be processed in an automatic, relatively effortless way facilitating efficient memory storage and retrieval (Slater, Buller, Waters, Archibeque, & LeBlanc, 2003). Second, stories generate emotional impact. Finally, stories may provide a source of information.

Child healthcare settings are not immune to the challenges of applying the best available research evidence to clinical practice, also known as knowledge translation (KT). Strategies that mobilise the use of research evidence to inform children’s healthcare can potentially reduce healthcare utilisation and high hospitalisation rates. Knowledge translation efforts to date have largely focused on ensuring that healthcare professionals use the latest research to inform their practice; however, recent evidence suggests that initiatives that target healthcare consumers can shape their treatment expectations which can further facilitate healthcare professionals' adoption of research-based practices (Slater et al., 2003).

Currently, there is an unprecedented demand for consumer friendly, reliable, evidence-based health information for patients and their families given the rapid increase in the development of research and its increased accessibility to the general public. Conventional mediums to transfer health information (e.g. standardized written instruction sheets) have been found by patients to be unsatisfactory in several aspects, but more specifically because they often contain both language that is too complex, and excessive medical jargon (Scott et al., 2009; Isaacman, Purvis, Gyuro, Anderson, & Smith, 1993; Hansen, 1995; Quan, Bennett, Cummings, Henderson, & Beccaro, 2001; Gittleman, Mahabee-Gittens, & Gonzalez-del-Rey, 2004). Previous research demonstrates that other more innovative mediums, such as cartoons and videos, are superior to traditional standard health sheets for transferring information to consumers (Delp & Jones, 1996; Austin, Matlack, Dunn, Kesler, & Brown, 1995). Thus, the use of narrative or stories holds promise as an innovative strategy for transferring research evidence to patients and families (Silver, 2001). The literature illustrates that storytelling is a tool to communicate with and influence individuals, yet there is still a need for evidence to confirm or refute its value as a knowledge transfer technique within the healthcare setting. Up until this point, limited research has explored using stories as an approach to transfer research-based information to parents in a child health setting.

In particular, there are two significant knowledge gaps in the use of stories in healthcare. First, the mechanisms of how stories 'work' or behave as a knowledge translation technique for healthcare consumers has not been explored. Second, the characteristics of effective stories for transferring health information to consumers have not been identified. Our study addresses these gaps through exploring the following research questions: 1) what are the characteristics of effective stories for transferring health information to parents? 2) How do parents use the stories? And 3) what are the outcomes that parents report when stories are used as a knowledge translation approach?

Croup

Croup is a common respiratory tract illness most often affecting children between 6 months and 3 years of age (Deny, Murphy, Clyde, Collier & Henderson, 1983). Croup accounts for a significant proportion of pediatric ED visits and hospitalizations (Hendrickson, Kuhn & Savatski, 1994; McConnochie, Hall, & Barker, 1988; Deny et al., 1983) and is characterized by a barking cough, hoarseness, inspiratory stridor, and often severe respiratory distress that can occur suddenly in the middle of the night. Strong research evidence supports the use of the drugs epinephrine and corticosteroids for the treatment of croup (Lenny & Milner, 1978; Wesley, Cotton, & Brooks, 1978; Klassen, Feldman, Watters, Sutcliffe, & Rowe, 1994; Osmond, 2002; Brown, 2002). Croup causes much anxiety for parents, largely due to the nature of the cough, difficulty breathing, timing of onset which often rouses children (and parents) from their sleep late at night, and their lack of knowledge regarding the condition (D’Angelo, McGillivray & Kramer, 2001; Williamson, 2005). The hectic and unfamiliar environment of the ED may further exacerbate this anxiety, creating a stressful situation that is less than ideal for information sharing.

Putting this Research Project into Context

This research project complements a randomized control trial (RCT) investigating the effectiveness of three storybooks that integrate research evidence regarding the epidemiology and treatment of croup into narrative format (‘stories’), as told by parents of children with the condition (ISRCTN39642997) (Hartling, 2010). This study and the RCT are two distinct, yet complementary studies. The results of the trial are currently being analysed and will be published separately. In the trial, effectiveness was assessed in terms of parental outcomes, such as anxiety and decisional regret, and resource use. Full details on the development and refinement of the stories, as well as detailed descriptions and illustrations from the storybook intervention, are published elsewhere (Hartling, Scott, Pandya, Johnson, Bishop & Klassen, 2010). Generally speaking the three books differ in several ways: each story reflects a case of different severity (mild/moderate/severe), and the appearance of the books differs in terms of size, shape, colour, writing style and formatting. However, each book contains a 12 page story written at a 6th grade level (equivalent to reading level for age 11-12), the same introductory message from the local pediatric Emergency Department director, and a final page outlining the main teaching points contained in the book. A creative writer, graphic designer, and illustrator were all actively involved in the development of the books (Hartling, Scott, Pandya, Johnson, Bishop, & Klassen, 2010). In the case of the randomized control trial, the parents received either the intervention (the suite of three books), or a standard information sheet. The control intervention was the standard patient information sheet which describes croup, signs and symptoms, management strategies, and when to consult medical services. The storybook or standard information sheet was given to the parents after they have been randomized to treatment groups at the beginning of their ED visit. Quantitatively measured parental outcomes were assessed through telephone interviews with the parents. These were conducted by research nurses the day after the emergency department visit and every other day thereafter until the child had recovered from the initial croup episode.

Research methods

An exploratory descriptive study adopting elements of grounded theory (Glaser & Strauss, 1967) was used to understand how stories were used by parents (assigned to receive the storybook intervention) as well as the social process through which the stories 'worked' to transfer knowledge to parents. Data collection, sampling and analysis all occurred simultaneously as the study progressed and sampling and further data collection was based on the emerging theory (Glaser & Strauss, 1967). Analyses also explored the essential elements of effective stories for transferring health information to parents.

Data Collection

Data were collected through semi-structured interviews of parents post ED visit ensuring that all pertinent information was obtained, while allowing participants the freedom to respond and illustrate concepts (Morse & Field, 1995). All interviews were conducted over the telephone by nurse researchers (SS, KOL) trained in qualitative methodology, and were subsequently taped and transcribed verbatim. The goal of data analysis was to describe the characteristics of stories that make them effective for knowledge transfer and to develop a thick, rich description of how parents used the stories. Interviews with parents lasted between 20 and 60 minutes. Parents were recruited through the pediatric EDs participating in the trial and only parents who received the storybooks participated in the qualitative interviews. The interviewer explained the purposes of the telephone interview, inquired if the parents were interested in participating, and explained the consent procedure. Interviews explored: 1) parents' perceptions of the effectiveness of the storybooks, 2) parents' experiences using the storybooks and 3) parents' perceptions on the elements of effective stories. The interviews began with the interviewer asking the participants to tell how they used the storybooks. Questions moved from the general to the specific (Bernard, 1994) with interviews later in the data collection period becoming increasingly more focused.

Data Analysis

The interviews yielded a large quantity of very complex data. To monitor the progress of the interviews and permit follow-up of ideas that emerge from the data, we conducted the interview, transcription, and analysis concurrently. Data analysis was conducted following the constant comparative approach developed by Glaser and Strauss (1967) and explained by Strauss and Corbin (1990). As categories emerged in the data analysis, subsequent interviews were used to explore these emerging categories. Consequently, while qualitative analysis progressed, the interviews became more precise and purposeful (Morse & Field, 1995). Data collection continued until saturation of major categories (Morse, 1995) was achieved. All cleaned qualitative data was uploaded into a qualitative data management software program, NUD*IST™ (version N6). This software program does not analyze the data, rather facilitates the organization of the data and its analysis. The process of data analysis was shaped by: 1) coding interviews; 2) sorting data to identify patterns; 3) generalizing constructs and theories; and 4) memoing to note personal reflections and insights (Cresswell & Miller, 2000). This analytic process was not linear; rather it was an iterative cycle between data collection and analysis.

All data provided by participants was coded, which facilitated analysis. The code word reflected the essence of the data that led to ease of recognition as the number of code words increased. Codes were operationally defined so that they could be consistently applied throughout. Coding was done jointly (SS, KOL) and consensus negotiated. Codes were placed into broad categories, which then formed the major unit of analysis. As categories emerged, their theoretical properties were defined. Categories were compared in an effort to locate similarities and differences between them. As categories were synthesized into themes, a broad, comprehensive and holistic view of the data was obtained.

Throughout the phases of the analytical process, memos were used as a record of the analytic process. As analysis progressed, memoing recorded and ordered the decisions and results of the analysis and aided in developing propositions within the data. Reliability of the categories and their constituents was confirmed by the frequency and consistency with which they were mentioned by participants during the interview process. Trustworthiness of the study findings was enhanced because of the iterative nature of data collection and analysis, and because the process involved two investigators, thus minimizing the chance of bias from a single perspective and expertise. Credibility or truth value was maintained by ensuring that the multiple perspectives of the parents were reported as clearly as possible. Applicability was assured through 'member-checking' and by asking participants to compare their experiences with others. Consistency was maintained by the careful documentation of all decisions made throughout the research process, and by regular meetings between the investigators to maintain unity to resolve any analytic discrepancies (Morse & Field, 1995).

Ethical approval for the study was received through the University of Alberta Health Research Ethics Board.

Findings

Twenty three parents were recruited and interviewed (Table 1). Nineteen interviews were with the child's mother, four with the child's father. Four themes emerged from the parent interviews: 1) parental perceptions of the stories, 2) the process of using the books, 3) the congruence of their individual ED experience with the story, and 4) outcomes related to using the stories.

Parental Perceptions of the Storybooks

Parents had largely positive perceptions of the stories. Generally, parents judged the accuracy of the information by comparing their own experience in the ED with the scenario in the book that most closely mirrored the severity (mild/moderate/severe) of croup experienced by their child. Most parents found that the stories accurately reflected their own experiences. In terms of the comprehensiveness, parents appreciated the three-book format, with each story addressing a different severity level. While not all of the information in each book was relevant for their specific situation, they acknowledged that some information would be useful for future croup occurrences. Parents stressed that portraying different scenarios based on severity helped them to differentiate between mild, moderate, and severe croup, which did, or would in future, allow them to pursue appropriate action.

Parents differed as to the appropriateness of the reading level (Kincaid Grade Level Score of 6.2) in the storybooks. One parent found the content to be too basic, simplistic, and of insufficient depth to be beneficial. However, the majority of parents acknowledged that the reading level was suitable given that the books were meant for people with a range of literacy skills. In comparison to the 'standard care' information sheets, participants felt that the storybooks would be more engaging and easier to read and assimilate.

> "Um, honestly, it's probably easier to read through and remember than it would be just to read through like the normal sheets of paper that they just give you." (Participant # 2)

The reasonable length of the stories was thought to hold the readers interest in contrast to the information sheet which would take longer to read and absorb.

Four parents were initially confused as to whether the books were meant for them or their children (or both). While most agreed that the books' written content was beyond the understanding of their child, the act of reading aloud to their child and/or viewing the pictures in the book held their child’s interest at least for a short period of time. Parents saw the books as having a two-fold purpose: educating parents about the diagnosis and treatment of croup, and providing a distraction for their children while they waited with their parents in the ED. Of note, one parent stated that the written information in the book was of primary importance and that the illustrations did not ‘add anything’ to the presentation of the material.

The Process of Using the Books

Both situational factors and individual parents’ learning needs dictated how the parents used the storybooks. For about half of the parents, the first reading of the books occurred in the ED while awaiting treatment. The rest of the participants stated that they waited until they were home for the initial read-through, citing the chaotic environment of the ED, lack of time, and the need to attend to their child as reasons for the delay in reading the books. While some of the parents described their use of the books as ‘skimming’ or ‘flipping through’ the material, most read through the stories more carefully. One parent described a process by which the stories were scanned for information relevant to their own situation, which then received more focused attention and was read more thoroughly.

> “I went right to the severe one...because that’s what he had...I read through the severe one ...really paid attention to it and then went back to the other two.” (Participant #6)

While all 3 books may have initially been ‘flipped through’ or ‘skimmed’, in most cases, parents more carefully read the book that matched the severity level of their own child before they read the other two books.

The portability of the books allowed them to be used in different location and situations, and by the same person several times, as well as by different individuals. Many of the parents read the books more than once, or stated that they would keep the books as an information source for any future croup occurrences. With the aim of helping other parents to be knowledgeable and prepared should their child develop croup, two parents mentioned that they had since passed the books on to other families. Of note, one parent mentioned that it was reassuring to have ‘written information’ to back up the verbal explanations and instructions they received from the healthcare professionals in the ED. In particular, they appreciated not having the added pressure of having to remember details that were given verbally during what they described as a stressful and tiring trip to the ED.

Congruence Between the Individual ED Experience and the Story

All of the parents described their child’s experience with croup and the resultant trip to the ED as anxiety provoking which mirrored the narratives described in the story. Uncertainty regarding the child’s diagnosis; potential complications, or when to seek out help for their child’s condition; were some of the reasons parents gave for their unease. Being unsuccessful at home in reducing both the fever and the barky cough associated with croup also contributed to parental anxiety and uncertainty. These parental experiences mirrored the experiences included in the narratives. Particularly worrisome for parents was the timing of the decision to seek out help for their child. They were unsure as to whether their child’s illness was quickly advancing into something serious, and whether or not it was appropriate to seek out medical care. They worried that if they went to the ED too early, they would be wasting time and resources on a condition that would eventually resolve on its own. This was countered with the worry that their child’s condition could potentially deteriorate quickly and dangerously if they waited too long to seek help.

Parents reported that if they had had the information contained in the books *prior to* their ED visit, they would have been better able to determine their child's croup severity level, which in turn would have helped them to decide with more confidence, the appropriate time for medical intervention. Because the timing of the books' distribution was after their arrival in the ED, not all of the parents were aware of (and therefore not able to employ) the strategies outlined in the stories (i.e. exposure to cold air); however, they felt that they would be better prepared to cope at home with future bouts of croup. One of the books (*A Late Night Trip to the Emergency Department*) contains a description of a mother struggling with the decision to go to the hospital for treatment of her child's croup. Parents felt that putting the information in the context of a story where characters experience a similar situation and emotions to their own, helped to validate their emotional reactions to their child's illness and also provided assistance in managing the situation.

> "I found that it also modelled some behaviours that parents could take whether it's checking the Internet or just the experience of being anxious and worried but coping with waiting for hours to see a doctor. So, I found them (the storybooks) helpful even just to suggest how to cope in that situation." (Participant #4)

Parents who had tried some of the strategies mentioned in the books (e.g. riding in the car with the windows down) albeit without success, felt satisfied with their decision to seek help because their experience was mirrored in the storybook.

Outcomes Associated With the Storybooks

Parents consistently reported four positive outcomes associated with using the storybooks: 1) feeling reassured that they had done the right thing, 2) reduced uncertainty, 3) normalization of the experience, and 4) feeling of empowerment. First, by presenting information about the signs, symptoms and treatment of croup, parents said that the storybooks assured them that they had ‘done the right thing’ by bringing their child to the ED for treatment. It also gave them the confidence that they would be able to handle whatever occurred once their child was able to leave the ED. In particular, knowing when to seek out help was particularly anxiety producing, and there was parental fear that inaction at a critical juncture in the croup trajectory could lead to a preventable deterioration of their child’s condition. While the decision to come to the ED had already been made in this instance, parents felt more confident about making the correct decision in the future, should their child (or one of their children) experience croup.

Second, parents said that a feeling of uncertainty accompanied the onset of their child’s illness. Some parents were unfamiliar with symptoms their child was experiencing (‘bark-like’ cough, fever, etc.), and for some who recognised the symptoms as being associated with croup, there was a lack of knowledge about how the illness is treated. Even for those parents familiar with croup and its treatment, uncertainty existed regarding the severity and progression of their own child’s illness. Parents acknowledged that croup (and croup symptoms) were “...not something you fool around with,” and they recognised an urgency in dealing with the illness. This fear and uncertainty was lessened by the provision of information whether it was from the health professionals themselves, the standard information sheet, or the storybooks—the key was getting the information

Third, parents reported that the stories normalized the experience of dealing with their child’s croup. Parents said they felt reassured that other parents had experienced similar emotions and this helped them to feel less ‘alone’ in what they were experiencing. Having a common bond with other parents who had gone through a similar scenario was important in decreasing their anxiety. The stories also helped them to realise that although a potentially serious illness, croup was relatively ‘common’ and that well established medical protocols existed to manage it. This was reinforced by having the treatment described in the books mirror the treatment their child received in the ED.

Fourth, parents reported that the stories empowered them through the provision of information. The two important aspects of ‘knowing’ about croup were ‘knowing what to expect’ and ‘knowing what to do.’ The former dealt with understanding the illness, its manifestations, progress, and treatment, while the latter dealt with knowing what actions were required to manage the illness. ‘Knowing what to do’ also included knowing *when* to take action. Of particular concern to parents was the timing of the decision to seek out the assistance of healthcare professionals. A number of parents mentioned that the information in the book supported their decision to come to the ED for treatment, and that they felt more secure in the knowledge that they had done the ‘right thing.’

Discussion

Our findings are an important advancement for knowledge translation by exploring the use of narrative or ‘storytelling’ as a means for transferring research-based information to parents. As well, we identified attributes of narratives (e.g., reading level, length, etc.) that parents consider important for successful knowledge translation.

Parental perceptions of the storybooks were largely positive, with the presented information being judged as accurate based on its consistency with parents’ experiences with the illness. This process of information validation is central to storytelling as the cognitive processes of recognition, relating, and understanding during the reading process have been identified as key elements to the success of stories as a knowledge transfer tool (Abrahamson, 1998). The story functions as a conduit of intellectual, cognitive and emotional understanding between the reader and teller through the sharing of like-experiences (Abrahamson, 1998). As parents gauged the stories as relevant for their specific situation, they were also able to project the need for the information in future circumstances. In this way, the parallels that were drawn between the storybooks and parental experience facilitated engagement and applicability of information to real life situations. Parents identified this level of usefulness to be an advantage in pursuing appropriate action in future circumstances.

We found that by accurately depicting similar experiences through story, the reader is potentially able to internalize the elements of the story and an interpersonal relationship between the story and reader may be formed. This largely interactive relationship may be exemplified through drawing parallels between the story elements to one's own experiences, and creating imaginative scenarios wherein different actions may have been taken (Cook, Taylor, & Silverman, 2004). The impact of such a relationship is both cognitive and emotional. The emotional impact is evident in our study findings when parents reported 'feeling reassured' and 'reduced uncertainty,' associated with the storybook use. These emotions further contributed to a sense of confidence in handling future occurrences. The stories also assisted parents in feeling 'less alone' during their ER visit and further assisted in reducing anxiety. The cognitive result is evident in the recurrent theme of 'normalizing' the experience of dealing with their child's croup, and demonstrated the common bond that can be created through story. Facilitating emotional reassurance, fostering confidence, and reducing anxiety promotes further cognitive reassurance and 'opens the conduit,' increasing receptiveness to information. This further facilitates knowledge transfer as it allows the reader to set aside existing belief systems and absorb information which may differ or challenge existing values and beliefs (Abrahamson, 1998).

Memory is predominantly story-based (Oatley, 2002) and as a result new information can more easily be integrated if it corresponds with an existing story component in memory. Such compartmentalizing, or indexing– the process where new information is related to existing memories and subsequently assimilated for future recall (Schrank, Berman, & Macpherson, 1999) is increased when many links can be made between the present story (Croup Books), and existing memory (previous parental experience). The stories included common elements experienced by families in similar situations through using composite narratives (bringing several parents' experiences together in one story). This approach facilitated the assimilation of new information with existing memory, providing the potential for a higher level of integration and ease of future recall when dealing with future occurrences of illness. The format of stories allowed for more links to be formed with existing memory, and it is through this process of indexing and understanding (index extraction) that parental confidence in dealing with future occurrences of illness could been increased. As well, the context of the story allowed for a high level of engagement with the research-based information. Engagement is an important characteristic in effective translation of knowledge through story as it allows for a level of 'awakening' for the involved recipient and a subsequent stronger relationship to life experiences (Abrahamson, 1998). This can assist in generating further insights into past and present experiences (Schrank, 1999). The learning that occurs when using story as a knowledge translation strategy for parents can be summarized into three components: experience, reflection, and explanation (Schrank, Berman, & Macpherson, 1999). The parental *experience* of their children's illness and subsequent management comprise an essential initial component in learning to effectively manage current and future episodes. Presentation of evidence-based information in a story format promoted integration of new information with existing experience in memory, through the indexing process. The process of indexing requires parental *reflection* upon how the situation was handled, both at home and in the ED. Finally, the research-based information presented in the story books provided *explanation* and rationale for treatments provided. This assisted parents in feeling reassurance that they did the right thing, and contributed to reducing anxiety and confidence for future situations.

Limitations

The most important limitation of this study is in the sampling method used. Because every participant who received a set of 'croup' storybooks was asked if they would consent to be interviewed, the final group of participants could be considered a self-selected sample, and therefore their views and opinions may not be representative of the population in general. Also, the ratio of female to male parents represented in the sample, while very close to that of the actual ratio reporting to the ED with a child with croup (Hartling, 2010), was weighted heavily in the former's favour. We did attempt to be as gender-neutral as possible (e.g. including a father as the main character in one of the storybooks), however we recognize that because of the high percentage of female respondents, our data may be less generalizable to male care givers. Despite these potential limitations however, our findings reveal important knowledge gains about evaluation of this knowledge translation tool.

Conclusions

The set of 3 croup storybooks were evaluated favourably by all 23 participants as a medium for conveying important health information to parents. Parents reported that through reading the stories, they were better able to understand the progression and treatment of croup, thus reducing uncertainty and alleviating anxiety about their child's condition. In identifying with the characters in the stories, parents were able to 'normalize' their experience and as well, have their emotions validated. This in turn provided them with a feeling of confidence in their ability to manage their child's croup and a belief that they had done 'the right thing.'

Practice Implications

Our findings have important practice implications for professionals who develop patient education tools. The short, portable format of the books was an important characteristic for parents. The short stories were regarded as 'easier to assimilate,' than standard written instructions, and the format allowed for future information access. Parents reported a variety of uses of the storybooks. The portability and variety of scenarios presented were regarded as important characteristics. The information, embedded in the familiarity of story, was accessible beyond the abbreviated encounter with trained health professionals. This format contributed to parental reassurance and parents appreciated 'not having the added pressure of having to remember details' from verbal explanations in the ED. The characters, context, and structure of the storybook presentation bound the information into a coherent whole that was regarded favorably by the parents who utilized them.

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Competing Interests

The authors have no competing interests to disclose.

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