Evaluation of a Storybook Resource for Parents in the Neonatal Intensive Care Unit

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ABSTRACT

This project evaluates the acceptability and utility of a storybook, entitled *Unexpected: Parents' Experience of Preterm Birth*, as an educational resource for parents in the neonatal intensive care unit (NICU). Forty-nine parents were recruited from Level II and Level III NICUs and completed several questionnaires; a subset of 11 parents also participated in focused qualitative interviews. Almost all parents experienced the characters as believable and agreed/strongly agreed that the stories accurately portray what it is like to be a parent in the NICU. The multiple narrators offer different perspectives of the NICU experience, which helped to normalize their experience and reminded them that they were not alone. Participants reported learning something new from the storybook and would recommend it to others.

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For most parents, having a baby born preterm (<37 weeks' gestation) is a traumatic experience and increases their risk of developing mental health problems such as depression, anxiety, and posttraumatic stress responses (Greene et al., 2015; Hynan & Hall, 2015; Jubinville, Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012; Kim et al., 2015;

Roque, Lasiuk, Radünz, & Hegadoren, 2017; Shaw et al., 2009). Findings from one qualitative study (Lasiuk, Comeau, & Newburn-Cook, 2013) revealed that preterm birth disrupts parents' expectations of parenthood. "Normal" disappears when parents step into the unfamiliar and frightening world of the neonatal intensive care unit (NICU), where their

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days are colored by changes in their baby's health. Parents' focus narrows, uncertainty remains high, and even subtle changes in their baby's situation can trigger a new crisis.

The high levels of distress underscore a need to educate and support parents through their experiences in the NICU and in the transition home. Psychosocial support initiatives for parents in the NICU should "normalize the levels of distress felt by almost all NICU parents and offer targeted and clinical levels of care for parents at risk" (Hynan & Hall, 2015, p. S2). To this end, we created a storybook, entitled *Unexpected: Parents' Experience of Preterm Birth*, and evaluated its utility as an educational resource for parents about the potential psychological, social, and emotional effects of preterm birth.

LITERATURE REVIEW

Psychosocial and Informational Needs of Parents in the NICU

For some parents, having an infant born preterm is a traumatic experience that confronts them with the fragility of human existence and disrupts their belief in the world as a just, orderly, and safe place (Janoff-Bulman, 1992). The American Psychiatric Association (1994, 2013) characterizes a traumatic event as one that involves experiencing or witnessing an event perceived to threaten the life or cause significant injury to oneself or a loved one. In the immediate hours and days after a traumatic event, distress is normative, and many people experience anxiety, intrusive thoughts, memories of the event in the form of flashbacks and/or distressing dreams, dissociation, and/or avoidance. When symptoms are severe and interfere with an individual's ability to function, they may meet diagnostic criteria for acute stress disorder (ASD). Depressive symptoms are also common. A study from one NICU reported that 28% of mothers and 17% of fathers of parents met criteria for ASD at 7–10 days after birth (Jubinville et al., 2012). Significant symptoms of depression were also present in 43% of mothers and 33% of fathers. For most parents, these responses spontaneously resolve within a month of

the traumatic event; however, if the symptoms persist beyond 30 days, individuals may go on to meet diagnostic criteria for posttraumatic stress disorder (PTSD; American Psychiatric Association, 2013). Over time, these symptoms can contribute to alterations in health, decreased quality of life, and impairment in social, occupational, or other aspects of day-to-day functioning (McFarlane, 2010).

Parents whose babies are born preterm and admitted to an NICU may struggle to grasp, accept, and adapt to their new reality. A systematic review of 60 studies (Cleveland, 2008) identified six priority needs of parents in the NICU, including "accurate, understandable information" (p. 672). Similarly, a review (Chertok, McCrone, Parker, & Leslie, 2014) of interventions to reduce stress among mothers in the NICU calls for evidence-informed interventions that address mothers' emotional and informational needs in a culturally sensitive manner.

Storytelling in Health Care

There is a growing body of literature regarding the use of narratives, stories, and storytelling in health care as a medium for diagnosis (Charon, 2006, Charon, 2012), treatment (Biggs & Hinton-Bayre, 2008; Williams, 2009), and education (Hartling et al., 2010; Hartling, Scott, Johnson, Bishop, & Klassen, 2013). Both engaging and validating, stories appeal to different ways of knowing than do the empirical and logical approaches used in traditional health information materials (Hartling et al., 2010; Hinyard & Kreuter, 2007). Constructing, listening to, and reading stories helps individuals to make sense of their lives because they help to organize and remember events in a coherent manner and to integrate thoughts and feelings into a meaningful gestalt (Pennebaker & Seagal, 1999). Once an experience has structure and meaning, emotions associated with that experience become more manageable (Pennebaker, 1992; Pennebaker & Chung, 2011). In addition to helping to make sense of difficult life experiences, stories convey information in a way that engages the reader/listener, while validating their own experiences. For these reasons, stories may be therapeutic as well as informative.

Unexpected: Parents' Experience of Preterm Birth

Findings of a qualitative study of parents' experience of having a preterm infant (Lasiuk et al., 2013) revealed that parents want psychosocial resources to help them to navigate through the psychosocial challenges of

having an infant in the NICU. This led researchers to approach the local NICU Family Advisory Care Team (FACT) to discuss the form and content these resources should take. The FACT, comprised of parents, nurses, nurse practitioners, physicians, social workers, and other NICU personnel, is dedicated to promoting family-centered care. Parents in the group stated that while they received ample information about the clinical and technical aspects of their babies' care, they lacked information about how to cope with the experience.

The research team then worked with a creative writer/book designer and photographer to create composite, fictional stories based on interview transcripts from Lasiuk et al. (2013) qualitative study. These stories reflect the first-person perspectives of four parents in the NICU: a first-time mother whose infant is newly admitted to the NICU; a mother whose infant has been in the NICU for several weeks; a father who is juggling paid work with supporting his partner and infant; and an NICU nurse with preterm twins. Our aims in creating the stories were that they be believable and engaging, appeal to a wide audience, and depict a variety of perspectives and experiences. We also recognized that the stress of having a baby in the NICU taxes parents' cognitive resources, so we wanted the stories informative but short and written in accessible language.

The stories were illustrated with black and white photographs and compiled into a 95-page, 8.5-inch square, soft cover storybook titled *Unexpected: Parents' Experiences of Preterm Birth*. The storybook also includes direct quotes from parents who participated in the original qualitative study, a glossary, and a self-care worksheet. The self-care worksheet provides a format for parents to identify self-care strategies to help them manage the stress associated with having an infant in the NICU (e.g., talking with supportive others). Before the storybook was self-published, it was vetted by the NICU FACT (Figure 1).

The objective of this article is to describe the development and evaluation of a storybook as an educational resource for parents about the potential psychological, social, and emotional effects of preterm birth. The research question motivating this project was—are stories an acceptable and useful approach for educating parents about the potential psychological, social, and emotional effects of preterm birth?

Figure 1. Unexpected: Parents' Experience of Preterm Birth.

METHODS

Ethical Oversight

The project was approved by the University of Alberta Research Ethics Board and the Conjoint Health Research Ethics Board, University of Calgary. It also received operational approvals from participating NICUs.

Design

This study employed an explanatory, sequential mixed methods approach involving questionnaires and interviews. Parents completed self-report measures of anxiety, depression, and stress to contextualize the study's findings along with a fit-for-purpose survey evaluating the storybook's content and format. Parental responses on the survey informed the interview guide for conversational interviews with a subset of 11 parents.

Setting and Sample

Recruitment took place at Level II and Level III NICUs in two large cities in Alberta, Canada. Parents were eligible to participate if they provided signed, informed consent; spoke and read English; and had a preterm baby (born <37 weeks' gestation)

In addition to helping to make sense of difficult life experiences, stories convey information in a way that engages the reader/listener, while validating their own experiences.

admitted to an NICU for a minimum of 1 week to ensure they had sufficient exposure to the environment and also some time to adjust to their circumstances. We enrolled 49 parents (both mothers and fathers) of preterm infants in Edmonton ($n = 25$) and Calgary ($n = 24$). Because the study was exploratory and descriptive in nature, a sample size of 49 was deemed sufficient. Edmonton participants were invited to participate in focused qualitative interviews about the storybook and 11 of them volunteered to do so. The conduct and analysis of these interviews constituted the second author's (JP) BScN Honors Project.

Data Collection and Analyses Procedures

Information letters describing the study were distributed by NICU research nurses (Edmonton) and unit clerks (Calgary). The letters included a "Permission to Contact" form that parents signed and returned, indicating their willingness to be contacted about the study. Parents who agreed to participate met with a research assistant who answered questions about the study and ensured they met inclusion criteria. Parents who agreed to participate were enrolled into the study, signed an informed consent, and completed a number of questionnaires.

Measurement

Demographics Survey. The Demographics Survey was developed for this study and elicited information about respondents' age, relationship status, education, ethnocultural background, and infants' gestational age.

After completing the questionnaires, participants were given a copy of the storybook to read and asked to complete the *NICU Storybook Evaluation Survey*. If the surveys were not returned within 7 days, parents were sent a text or email reminder. Only one participant did not return the survey.

Edinburgh Postnatal Depression Scale. The Edinburgh Postnatal Depression Scale (EPDS; Cox, Holden, & Sagovsky, 1987) is a widely used, 10-item self-report tool that asks respondents to rate their mood over the past week. Items include statements such as "I have been anxious or worried for no good reason," "I have felt sad or miserable," and "I have been so unhappy that I have had difficulty sleeping." Each item is scored from 0 to 3 and scores from all items are added to produce a total that can range from 0 to 30. A score > 10 suggests

"possible depression," while scores ≥ 12 suggest "probable depression." Item 10 asks about thoughts of self-harm. Respondents who score 1, 2, or 3 on this item require further assessment for self-harm/suicidal ideation and/or behavior. A systematic review of 37 studies validating the EPDS reported its sensitivity for major depression ranged from 57% to 100%, and its specificity ranged from 93% to 99% (Gibson, McKenzie-McHarg, Shakespeare, Price, & Gray, 2009). Matthey, Barnett, Kavanagh, and Howie (2001) also validated the EPDS for use with men, however, they suggest a 2-point lower cutoff score than for women (i.e., 5/6).

Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a self-report screening tool for anxiety and depression developed for use in nonpsychiatric populations. Its 14 items, seven each for anxiety (HADS-A) and depression (HADS-D), ask about the relative frequency of symptoms in the past week on a 4-point scale ranging from 0 (*not at all*) to 3 (*very often*). Total HADS scores can range from 0 to 42, with higher scores indicating greater symptom severity. In a systematic review of 747 studies, Bjelland, Dahl, Haug, and Neckelmann (2002) identified a cutoff point of 8/21 as indicating clinically significant symptoms for each subscale. In that review, the HADS-A had a specificity of 0.78 and a sensitivity of 0.9, whereas the HADS-D had a specificity of 0.79 and a sensitivity of 0.83.

We intended to examine the incidence of ASD, however, most parents who volunteered for enrollment had been in the NICUs for a significant period (average in Calgary = 25.6 days, and in Edmonton = 37.9 days). Since ASD can only be diagnosed in the first month after exposure to a traumatic event, we could only administer the clinical assessment tool (Acute Stress Disorder Interview) (Bryant, Harvey, Dang, & Sackville, 1998) to a minority of parents. Of the parents screened for ASD, only one reported a score that indicated the presence of ASD. She was referred for further assessment.

NICU Storybook Evaluation Survey. Developed for this study, the NICU Storybook Evaluation Survey contained statements about the storybook's acceptability (i.e., physical characteristics) and utility and asked respondents to indicate their level of agreement/disagreement with each statement on a 6-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The survey also

provided space for participants to include narrative responses to every statement.

Qualitative Interviews

Eleven Edmonton parents also participated in interviews about the storybook. These semistructured, conversational interviews were conducted in person or by telephone and began with an open-ended invitation asking parents to share their response to the storybook. The interviewers (JP or GL) followed up with probes and closed-ended questions to elicit more specificity and detail about participants' responses to the book's format (e.g., physical size and shape, book design, photographs, etc.), content (e.g., accessibility of the language, fidelity with their NICU experience, and believability of the characters and stories), and usefulness as a resource. Interviewers were also interested in how parents interacted with the storybook and inquired whether (a) they would spontaneously pick it up and read it if they saw it lying somewhere, (b) the characters and their circumstances were believable, (c) parents could see themselves in the stories, and (d) they learned something from the stories.

The interviews were digitally recorded, transcribed, and analyzed following the traditions of Interpretive Description (Thorne, 1998; Thorne et al., 1997). Interpretive Description is ideal for "smaller scale qualitative investigation[s] of a clinical phenomenon of interest to the discipline for capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding" (Thorne, Kirkham, & O'Flynn-Magee, 2004, p. 5).

RESULTS

Descriptive statistics were generated to describe participant characteristics. Frequencies and percentages were calculated for categorical and discrete variables and means, standard deviations, and ranges were calculated.

The majority of parents were women over 30 years of age ($M = 31.8$, $SD = 6.1$), predominately Canadian-born (78%), with English as a first language (73%), and married and living with a spouse (78%). Participants were well educated (above a high school diploma, $n = 29$; 59%) and of a relatively high socioeconomic status (income $> \$60,000$ per year, $n = 32$; 65%) (Table 1). The mean gestational age of the infants was 31.8 weeks (range 19–43; $SD 6.1$). On average, babies in Calgary had

shorter NICU stays than the Edmonton babies (25.6 ± 28.4 days vs. 37.9 ± 29.8 days). There were no statistically significant differences between the parent and infants in Edmonton and Calgary (Table 2).

The mean score on the EPDS was 9.2 (range 1–25; $SD 5.3$) (Table 3), which is just under the cutoff score of 10 indicating possible depression (Cox, Murray, & Chapman, 1993). Parents in Calgary had slightly higher mean EPDS scores (9.9; $SD 8.5$) compared with those in Edmonton (8.5; $SD 4.4$). The mean total HADS score was 13.3 ($SD 7.0$), suggesting that all parents were experiencing some distress. A χ^2 test for independence (with Yates' continuity correction) was performed to determine if there was an association between depressive symptoms on the EPDS and the HADS-D subscale. Scores > 8 indicate the presence of clinically significant depressive symptoms on the HADS-D, and a score ≥ 10 on the EPDS suggests possible depression. As expected, there was a significant association between depressive symptoms on the HADS-D and the EPDS ($\chi^2 [1, N = 49] = 8.45$, $p = .004$, $phi = .415$). Seventy-seven percent (10/13) of parents who reported symptoms indicative of depression on the EPDS (scores > 10) also had HADS-A scores indicating the presence of anxiety symptoms (HADS-A score > 8).

Evaluation of the Storybook: Qualitative Findings

Parents provided feedback about their first impression of the storybook and its acceptability and utility (Table 4).

First Impression. Most parents (86%) agreed/strongly agreed that they would spontaneously pick up the storybook and read it. As one parent explained, "anything with the word 'preterm' or 'NICU' catches my eye." Other parents would be inclined to pick it up because they "really enjoy reading [anything to do with prematurity]" and the cover illustration and title were appealing. One parent emphasized the importance of having an attractive photograph on the cover, because a "scary" cover may deter some parents from opening a book. A parent who would not spontaneously reach for the book explained, "...from the look of it, it would have been a longer read" and her energy for reading was limited. Another parent would have avoided it "due to anticipated effects on emotions." A few parents thought that the storybook should be offered to

TABLE 1.
Parent Demographics

Variables	Calgary (n = 24)		Edmonton (n = 25)		Combined (n = 49)	
	n	(% ^a)	n	(% ^a)	n	(% ^a)
Gender						
Female	20	83	21	84	41	84
Male	4	17	4	17	8	16
Education						
Junior high	0	0	2	8	2	4
High school/equivalent	6	25	9	36	15	31
Trade/technical/vocational	3	13	7	28	10	20
Bachelor's degree	12	50	5	20	14	35
Master's degree	3	13	2	8	5	10
Income						
<\$9,999	4	16	0	0	4	8
\$10,000–\$19,999						
\$20,000–\$39,999	2	12	3	12	5	10
\$40,000–\$59,999	3	12	3	12	6	12
\$60,000–\$79,999	0	0	7	28	7	14
\$80,000–\$99,999	4	16	2	8	8	16
> \$100,000–\$149,999	10	42	2	8	17	34
Missing	1	4	1	4	2	4
Relationship status						
Common-law/live-in partners	3	13	1	4	4	8
Engaged	1	4	2	8	3	6
Married and living with spouse	18	75	20	80	38	78
Separated	0	0	1	4	1	2
Single, never married	2	8	1	4	3	6
First language						
English	15	63	21	84	36	73
Other	9	38	4	16	13	27

^aPercentages were rounded to the nearest whole percent.

parents only after they had spent at least a week in the NICU. Although she would not have picked the book up on her own, another parent said, “now that I’ve read it, I would pick it up and recommend it.”

How Did Parents Interact With the Book?

Virtually all of the participants (97.9%) read the entire text. Approximately a third (32.6%) did so in a single sitting, while others (63.2%) read the book in multiple sittings in between caring for their babies. Many of the mothers read the book while performing activities like pumping breastmilk or commuting to the hospital. For some, reading the book was a break:

...because you’re always doing something in the

NICU ... Like, you do your kangaroo care, you do your diapering, you do your cuddling, and then you put him back so he can have his own time to sleep and rest, and then that’s your time.

When we asked parents about how they interacted with the storybook, the majority responded that they were drawn in by the stories:

I had to stop at the first page—it made me cry—remininded me of my first meeting my son. Then I read it from start to finish. I could not put it down even when the tears were flowing.

Many parents endorsed the multiple narrators because they made the stories “feel more real,”

TABLE 2.
Infant Demographics

Variables	Calgary (N = 24)			Edmonton (N = 25)			Total (N = 49)		
	M	SD	Range	M	SD	Range	M	SD	Range
Gestational age (weeks)	32.5	6.3	20–43	31.0	6.0	19–42	31.8	6.1	19–43
Length of NICU stay (days)	25.6	28.4	1–122	37.9	29.8	7–105	32.0	29.5	1–122

Note. SD = standard deviation.

TABLE 3.

Measures of Parental Anxiety and Depression

Variables	Calgary (N = 24)			Edmonton (N = 25)			Combined (N = 49)		
	M	SD	Range	M	SD	Range	M	SD	Range
HADS score	13.4	8.5	2–36	13.2	5.4	4–25	13.3	7.0	2–36
EPDS score	9.9	8.5	1–25	8.5	4.4	1–19	9.2	5.3	1–25

Note. SD = standard deviation.

provided opportunities to see others' perspectives of the NICU, and gave them the sense that they were not alone. Parents also commented that having multiple characters enabled them to relate to at least one of the characters. One mother stated that she related to different characters at different points during her stay in the NICU, and another

would have liked even more stories to be included in the book. Many of the comments about the multiple narrators focused on the inclusion of a father's perspective. One mom told us,

The section from the husband's point of view was by far the most helpful. I hadn't thought about how

TABLE 4.

Evaluation of the Storybook (N = 49)

Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	No Response
1. I would pick up this book if I saw it somewhere.	0	4	2	30	12	1
2. The book's size and shape made it easy to hold and read.	0	3	1	27	18	0
3. I think an electronic (digital) version of this book would be a good idea.	0	6	16	22	5	0
4. I liked the pictures in the storybook.	0	2	4	29	14	0
5. I prefer black and white photos in the book to color photos.	1	8	16	19	5	0
6. The print (font) size makes the book easy to read.	0	0	0	24	25	0
7. The print (font) color makes the book easy to read.	0	2	0	23	24	0
8. The amount of text (number of words) per page makes the book easy to read.	0	1	0	23	25	0
9. The book is too long.	16	29	2	2	0	0
10. The stories are believable.	0	1	0	23	25	0
11. The photographs in the book show what it is like to be a parent in the NICU.	1	0	4	27	16	1
12. This book would help others know what it is like for parents in NICU.	1	1	1	31	15	0
13. I liked that the book included quotes from parents.	0	0	4	29	16	0
14. The glossary at the end of the book was useful.	0	0	9	24	16	0
15. I would recommend this book to other parents in NICU.	0	1	3	23	21	1
16. I read the book from start to finish in one sitting.	2	14	2	11	20	0
17. I paged through the book and only read parts of it.	31	12	1	4	0	1
18. I only looked at the pictures and did not read the text.	36	12	0	0	0	1
19. I completed the self-care checklist at the back of the book.	10	17	4	12	4	2
20. I learned something new from the book.	1	9	4	30	4	1
21. Overall, this book was helpful.	0	1	3	35	10	0

Note. NICU = neonatal intensive care unit.

hard it is for him to have me only think of our baby. He needs my support too.

Parents also told us that the couple's argument in the story reflected their own arguments and one woman said that the fictional husband matched hers "to a 't'."

Format

Size, Shape, and Length. A majority of parents endorsed the book's size and shape (91%) and length (91%), saying it was "just right" and "the perfect length." Some parents would prefer a taller and narrower version, and others noted that the book was an irregular shape if one wanted to tuck other papers into it. One participant told us, "It's too long to read in one sitting but because it's divided into 'chapters' you can read one or two at a time and take a break." Some parents were glad that the book was not "a big long war novel with no pictures" and liked the combination of text and photographs. Others wished the book was longer:

I probably could have kept reading more ... because I thought it was so relatable, I thought, "Oh! They should write a whole book about this kind of experience, like a thick book, a novel."

Parents were mixed on their desire for a digital version of the book. Fifty-five percent ($n = 27$) parents agreed/strongly agreed that they would like a digital version; 33% ($n = 16$) were neutral; and 12% ($n = 6$) disagreed. Parents who favored a digital version referenced the ease of reading a digital book with one hand during activities like kangaroo care or pumping breastmilk, and the convenience of digital resources. One parent noted:

Digital is awesome, I have everything on my iPad and iPhone, so it would have been ... more easy and convenient to just flip through it there ... it's just one less thing to carry around, one less thing to find a place for, from an economical point of view, one less—you know, tree cut down for the paper and pages.

Photographs. Parents agreed/strongly agreed (88%) that they liked the photographs in the storybook and that the images revealed what it was like to be a parent in the NICU (88%). They commented that the images "added a lot to the impact of the story," making them

"believable" and enabled them to "instantly relate."

It's nice to see what you're going into so you know what to expect and aren't shocked by it.

I've got almost identical pics on my camera. Good job.

Just under half of the participants (49%) preferred black and white photographs to color. Proponents thought that this option was "classic," impactful, emotional, and allowed the viewer to see "what we're trying to tell you [without] distraction." One parent told us that the black and white coloring reflects their own experience of life in the NICU as "colorless," while another suggested a combination of black and white and colored photographs.

Content

Virtually all participants (98%) agreed/strongly agreed that the stories are believable and reveal what it is like to be a parent in the NICU (94%). A majority (92%) rated the book as helpful and would recommend it to others (90%). Parents who participated in interviews about the book reported that they "liked" or "enjoyed" it because it was "relatable," "helpful," and made some parents "grateful" that their situation was not worse. A few parents told us that the book made them cry. When asked to elaborate, one parent said,

I think you cry because it hits home, you know? So very relatable, nice to hear other parents' perspectives.

I think it's hard to understand when you're not going through it yourself and often it's hard to talk about your feelings with others. This book would definitely help to illustrate the feelings, happy and sad, that parents go through.

For some, the book was a welcome alternative to the "pamphlets [that are available] on everything." The stories helped some parents to "learn better" and provided more detail than the bulleted points used in many pamphlets. When asked if they would recommend the storybook to others, parents responded:

I would recommend [the storybook to others] because it would help them to understand the fact that they are not alone, a lot of parents are going through this traumatic phase.

I plan to pass this along to my sister to share the

experience with her. My story is on many of these pages.

One participant wrote that the storybook “should be given/shown/suggested to all NICU parents,” to “those who are at risk for early labor or who could be induced early,” and to “expecting parents, just so they know the possibilities.” Another believed that the book should be given to parents “after a week about [in the NICU],” while another noted that “some parents might find it too much as it can be busy days in the NICU for already overwhelmed parents.”

Auxiliary Material. Only about one third of parents (33%) used the self-care checklist at the back of the storybook because they felt they were already “coping well,” they did not notice it, and “already [had] a self-care checklist elsewhere.” Several parents told us that they “read and thought about it ... [but] did not actually WRITE in back” and that “it was helpful because it made me think about those things.”

Many parents (82%) thought the glossary was useful:

[T]here's so much to remember ... all at once.

I did get my mother to read the book when I got home, and she used the glossary a lot more because she didn't understand all of the stuff ... when she read it, she's like, “Is that really what it was like? ... Really? Is that what you really went through?” And I was like, “Yeah, that's what it was like.”

Suggestions for improving the glossary included adding “slangy terms” or often abbreviated terms such as “desat” or “NG tube.” Another suggestion was to include a photograph of each machine along with the definition to create a visual glossary.

Utility. Most parents (69%) agreed/strongly agreed that they learned something new from the book. This number may reflect our recruitment method, which favored parents with longer NICU stays. As one parent noted,

...it would have been different had it been my first time through [the NICU] ... like, my answers probably would have been a lot different. But, being three times through, I've learned most of what you can learn.

Many parents found the book helpful because it gave them the sense that they were not alone in their

experience. Throughout the written comments and interview transcripts, the same phrase was repeated: “It's nice to know that we are not alone.” Parents explained the significance of not being alone as a source of comfort and hope. One parent said:

It made my experience feel more universal. I knew I wasn't the only one to have certain thoughts or feelings but they were certainly validated by reading them so closely described in text. This book is very well done [and] I'm thankful to have read it.

I've been suffering a lot of—feeling like I did something wrong and that's why we ended up in the NICU, and things like that. So, reading the book helped me realize that ... I did everything I could for my son, and really that's all I could ask of myself. So it was nice to get that kind of—not closure, but that kind of positive reinforcement...

Parents also thought the book was helpful because they could relate to it. As one mom said, “being able to relate, knowing I'm not the only mom who had serious ups and downs in my mood—its nice knowing someone else has been here + (sic) survived.” The parents who did not find the book helpful had been in the NICU for several weeks before they read the book, had previous experience in the NICU, or had other supports. One mom noted “the emphasis on the relationship between mothers at the NICU to be foreign, since [she had] not had that experience at all.” Another commented that, although “the book didn't really help” it reminded them “of how far” they had come, which was “refreshing.”

DISCUSSION

We created a storybook, entitled *Unexpected: Parents' Experience of Preterm Birth*, through a multistaged, collaborative process involving academic researchers, a writer/book designer, a photographer, and NICU parents and personnel. The book's four characters and their first-person stories drew from an earlier qualitative study (Lasiuk et al., 2013) to inform parents about some of the potential psychological, social, and emotional effects of preterm birth; to normalize their experience of distress; and to suggest some self-care strategies. The current project evaluated the book's acceptability and utility as a psychoeducational resource for parents.

Overall, parents' evaluation of the storybook was very positive. Almost all participants experienced the stories and characters as believable and reported that

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they accurately portray what it is like to be a parent in the NICU. Parents also endorsed the book's multiple narrators as believable, as offering different perspectives of the NICU experience, which normalized their experience and reminded them that they were not alone. Parents' experience of being drawn into the stories is consistent with Gerrig's (1993) notion of "transportation" (p. 12) and helps to explain why stories can be an effective means of communicating health-related information to positively influence attitudes, beliefs, and behavior. Gerrig (1993) used the metaphor of traveling to describe how engrossment in a novel can transport a reader away from his or her world of origin, which then becomes inaccessible to them for a time, and to which they return changed by the journey. Elaborating on this, Green and Brock (2000) developed the narrative transportation model to explain the persuasive power of stories conveyed in textual, audio, and visual formats.

In their transportation-imagery model, Green and Brock (2000) describe narrative transportation as a mental state during which there is "an integrative melding of attention, imagery, and feelings, focused on story events" (Green, 2006, p. 247). More recently, van Laer, de Ruyter, Visconti, and Wetzels (2014) defined narrative transportation as "the extent to which (1) a consumer empathizes with the story characters and (2) the story plot activates his or her imagination, which leads him or her to experience suspended reality during story reception" (pp. 799–800). As their absorption in the story increases, the reader/listener/viewer's awareness of time and place diminishes, as does their access to real-world facts that are incongruent with those presented in the story (Green & Brock, 2000). In this transported state, individuals are purportedly open to persuasion because they are so captivated by the story that they are less likely to argue with its propositions and they identify with or develop strong emotions for the characters, which gives the characters' perspective greater influence on the beliefs of the reader/listener/viewer (Green, 2004; Green & Brock, 2000; Green & Fitzgerald, 2017). Research into narrative

transportation suggests that stories that are more transporting are more likely to influence attitudes toward consumer products (Escalas, 2004) and affirmative action policies (Mazzocco, Green, Sasota, & Jones, 2010), and health-related knowledge, attitudes, and behavioral intention associated with cervical cancer screening (Murphy, Frank, Chatterjee, & Baezconde-Garbanati, 2013).

Through their meta-analysis of the antecedents and consequences of narrative transportation, van Laer et al. (2014) found that narrative transportation requires consumers to process stories, that is, to receive and interpret them. Story readers/listeners/viewers are transported through two phenomena: empathy (Slater & Rouner, 2002) and mental imagery (Green & Brock, 2000). By empathizing with a story's characters, the story receiver identifies with the character and gains access to the character's inner world. Empathy enables the story receiver to detach from their own experience and, for a time, to inhabit the experience of story characters. In doing so, they have an opportunity to know and feel what the character knows and feels. Through mental imagery, story receivers create mental images of the story plot, which enables them to experience the events themselves. Although more empirical work is needed to understand the persuasive effects of narrative transportation, van Laer et al. (2014) hypothesize that when a story transports a story receiver, it reframes their language related to the story events, thereby changing the world to which the story receiver returns.

In the current project, a repeated theme in parents' comments was their ability to relate to the stories and identify with the characters, which is necessary for stories to be effective (Schank & Berman, 2002; Slater, Buller, Waters, Archibeque, & LeBlanc, 2003). This underscores the need for end-user involvement at all stages in the story development to ensure identification with the characters and situation to maximize the effectiveness of stories as vehicles for health teaching. Hinyard and Kreuter (2007) concur that "...when [readers] connect to characters in the narrative, these characters may have greater influence on the audience members' attitudes and beliefs" (p. 785). This endorses the use of stories for health teaching and therapeutic potential.

During the development of the storybook, we incorrectly assumed that parents in the NICU have a great deal of time to read. This was not the case and parents in this study had to fit their reading in

around caring for their infant. The organization of the storybook into sections enabled parents to read it over a number of sittings. A related finding is that parents often read the storybook while engaged in other tasks such as kangaroo care and pumping breastmilk. To facilitate this, some parents want a book that is small and light enough to be managed with one hand. Over half of parents would like a digital version of the storybook. This may be a consideration in the future development of health resources for NICU parents, although in some settings cellular telephones may be prohibited and Wi-Fi may not be available.

Limitations

The limitations of our study also suggest areas where more research is required. A consideration when studying vulnerable populations is not to add additional burden. To prevent this, we worked with NICU research nurses to establish contact with parents. This, however, was a source of bias in our sample, as the nurses approached parents who had been in the NICU for longer periods of time and who were perceived as more “stable.” This was evident in some parents’ comments regarding what they learned, their use of the glossary, and their recommendations for appropriate audiences. It was also apparent in the differences in mean lengths of infants’ stay in the Edmonton and Calgary NICUs (25.6 days vs. 37.9 days). Future work should focus on evaluating the storybook within 7–10 days postadmission.

Although our sample included parents whose scores on the HADS and EPDS suggest the presence of clinically significant anxiety and depression, it is possible that their mood may have influenced parents not to participate. It is also important to note that our book was only offered in English. This points to the potential for translating the storybook into other languages and to include more cultural references. Other limitations include the small sample size and the use of self-reported screening tools versus diagnostic interviews. As well, the small number of male participants ($n = 4$) meant we could not examine differences between fathers and mothers.

CONCLUSION

The findings of this study add further evidence that storytelling is an acceptable and effective approach for health teaching in the NICU. Through narrative transportation, stories and storytelling convey

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