



Positive impact of an inpatient early childhood literacy programme on literacy practices and family experience in a paediatric heart centre




Original Article

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Abstract

Objective: CHD predisposes children to neurodevelopmental delays. Frequent, prolonged hospitalisations during infancy prevent children with heart disease from participating in recommended language and cognitive development programmes, such as outpatient early childhood literacy programmes, and contribute to caregiver stress, a risk factor for adverse developmental outcomes. This study aims to describe the implementation of a single-centre inpatient early childhood literacy programme for hospitalised infants with heart disease and assess its impact on reading practices and patient–family hospital experience. **Methods:** Admitted infants ≤1 year old receive books, a calendar to track reading frequency, and reading guidance at regular intervals. Voluntary feedback is solicited from caregivers using an anonymous, QR-code survey on books. A prospective survey also assessed programme impact on hospital experience. **Results:** From February 2021 to November 2023, the Books@Heart programme provided 1,293 books to families of 840 infants, of whom 110 voluntarily submitted feedback. Caregivers reported a significant improvement in access to books ($p < 0.001$) and increased reading frequency after learning about Books@Heart ($p = 0.003$), with the proportion reading to their child daily increasing from 27% to 62%. Among 40 prospective survey responses, caregivers reported feeling a sense of personal fulfillment (60%), self-confidence (30%), connection (98%), and personal well-being (40%) while reading to their child. **Conclusion:** An inpatient early childhood literacy programme is a well-received intervention for infants with heart disease that promotes development, improves book access, increases reading exposure, and engages families. Further studies are needed to assess its impact on sustained reading practices and neurodevelopmental outcomes.

Introduction

The number of patients with congenital heart disease (CHD) living into adulthood is growing rapidly due to medical and surgical advancements.¹ Both biological and environmental factors predispose this population to neurodevelopmental delays, including motor, cognitive, and language deficits. These can translate into difficulties with inattention, hyperactivity, and need for remedial services in school and must be addressed to optimise quality of life.^{2–7} Hence, in addition to outpatient neurodevelopmental follow-up for all children with CHD, the American Heart Association has called for prioritising research and implementation of developmental care in the inpatient setting, especially for children undergoing intervention in infancy and early childhood.^{2,8} However, while the American Heart Association has published a science advisory defining key components of developmental care for children with CHD, there is no consensus guideline for optimal developmental care of hospitalised infants with CHD or infants hospitalised with other forms of heart disease, such as heart failure, heart transplantation, or arrhythmias.⁸

Further, parents of hospitalised infants often report significant levels of psychosocial stress, depression, and anxiety,^{9–12} which are associated with adverse behavioural and developmental outcomes in their children.^{2,13,14} Contributing to these feelings, parents experience altered parental roles, including difficulties in engaging in developmentally appropriate activities like shared reading with their children.^{15,16} This is exacerbated by barriers including an often overwhelming environment, competing responsibilities, and misunderstandings about developmentally appropriate activities.¹⁷

In general paediatric practice, the outpatient early childhood literacy programme Reach Out and Read is a well-studied primary care initiative that provides books and developmentally appropriate anticipatory guidance about reading to families.¹⁸ This combination of interventions has been shown to improve access to books, increase reading practices at home, as well as improve long-term language outcomes, especially among families with a lower socio-economic status.^{19–24} However, there are no reports on the utilisation of such a programme in the inpatient setting in a heart centre. For a patient population that has prolonged and frequent hospitalisations, such as infants with heart disease, an inpatient early childhood literacy programme may offer a unique opportunity to engage patients and caregivers to target modifiable risk factors for developmental delay, such as environment and caregiver mental health.^{8,25} In this study, we describe the implementation of an inpatient early childhood literacy programme as part of inpatient family-oriented developmental care in a referral paediatric cardiac programme and describe its impact on literacy practices and caregiver hospital experience.

Materials and methods

Healthcare setting

Texas Children's Hospital is a large academic institution with a quaternary care cardiac centre that performs over 1,000 cardiac surgeries per year, including over 250 infant cardiac surgeries. The Texas Children's Hospital Heart Center inpatient unit consists of 48 cardiac Intensive Care Unit (ICU) beds and 42 cardiac acute care beds. The inpatient developmental care programme includes a multidisciplinary team that conducts weekly developmental care rounds to provide support and developmental guidance to families prior to discharge home.²⁶ The institution's Cardiac Developmental Outcomes Program provides longitudinal outpatient neurodevelopmental follow-up for patients from the Texas Children's Heart Center.

Description of programme

The Texas Children's Hospital Heart Center created and launched the inpatient early childhood literacy programme named "Books@Heart" in February 2021. It was initially implemented in the cardiac ICU as part of routine infant developmental care and was then expanded to the acute care cardiology ward in response to family feedback. The programme was created with the following transformational aims: (i) to provide inpatient language-based and cognitive-based developmental care, (ii) to improve patient-family engagement and experience, and (iii) to improve long-term neurodevelopmental follow-up of infants hospitalised with heart disease. The multidisciplinary Books@Heart team includes physicians, advanced practice providers, nurses, speech and language pathologists, physical and occupational therapists, and volunteers. Programme materials, including books and rewards, are funded both through the institution's Heart Center and philanthropic donations and stored at each patient location for easy access by team members.

As described in Figure 1, all infants under 1 year of age admitted to the Heart Center with congenital or acquired heart disease, cardiomyopathy, or arrhythmia receive an age-appropriate book on admission in the family's preferred language (English or Spanish), as well as at 2, 4, 6, 9, and 12 months of age, if they are

either still hospitalised or readmitted. Along with a book, each infant and family are also given a reading calendar with stickers to keep track of reading frequency, which is documented at weekly intervals by a Books@Heart team member. At initial contact in either the cardiac ICU or acute care cardiology ward, a team member gives all qualifying families developmentally appropriate anticipatory guidance about how to read to their child, the benefits of early language exposure, and encouragement to read to their child, regardless of the patient's level of acuity. Certified medical interpreters were used if indicated. Team members also provide incentives based on reading frequency, including medals, trophies, and new books. Newly admitted patients, those already receiving materials from Books@Heart, and discharged patients are all tracked through shared lists in the electronic medical record. Reading exposure is tracked in a secure database maintained at the hospital. Bedside nurses and therapists are also encouraged to read to the infants. A partnership with the hospital's summer volunteer program has supported two school-aged student volunteers reading to the infants in a precepted manner, on two afternoons per week during the months of June and July in 2022 and 2023.

Reading practices and access to books

A voluntary, electronic, anonymous feedback survey (Survey 1 - Supplemental Figure S1) has been provided to caregivers since May 2021, to seek feedback on their satisfaction with the programme and its offerings, any barriers to reading in the hospital, self-reported reading frequency and access to books, and suggestions for improvement. It also includes an opportunity for free form responses. This survey is provided to all caregivers of participating patients in the cardiac ICU and acute care cardiac ward through a QR code on each book and bookmark distributed.

Programme feedback and family hospital experience

To specifically seek information about the program's impact on the inpatient family experience in the Heart Center, a prospective project (approved by Baylor College of Medicine Institutional Review Board) was pursued. After confirming caregiver interest and obtaining verbal consent to participate, we distributed a written, voluntary, anonymous survey (Survey 2 - Supplemental Figure S2) to caregivers from January to May 2023 to determine the impact of the inpatient early childhood literacy programme on family hospital experience and to further assess family perception of the programme. The survey questions were developed based on the Maslow's hierarchy of needs²⁷ and a previously reported survey of families participating in a neonatal ICU-based reading programme.²⁸ This survey also included an opportunity for free-form responses.

Analysis

Descriptive statistics for the overall cohort included frequencies for reported reading sessions, books distributed, and reading awards, as well as categorical responses to survey questions. Chi square test was used to compare reading frequency and access to books prior to and after Books@Heart. To perform a qualitative exploratory analysis, free form responses for both surveys were read and labelled with core themes using an inductive emergent theme identification approach. SPSS 28.0 (IBM) was used for analysis.

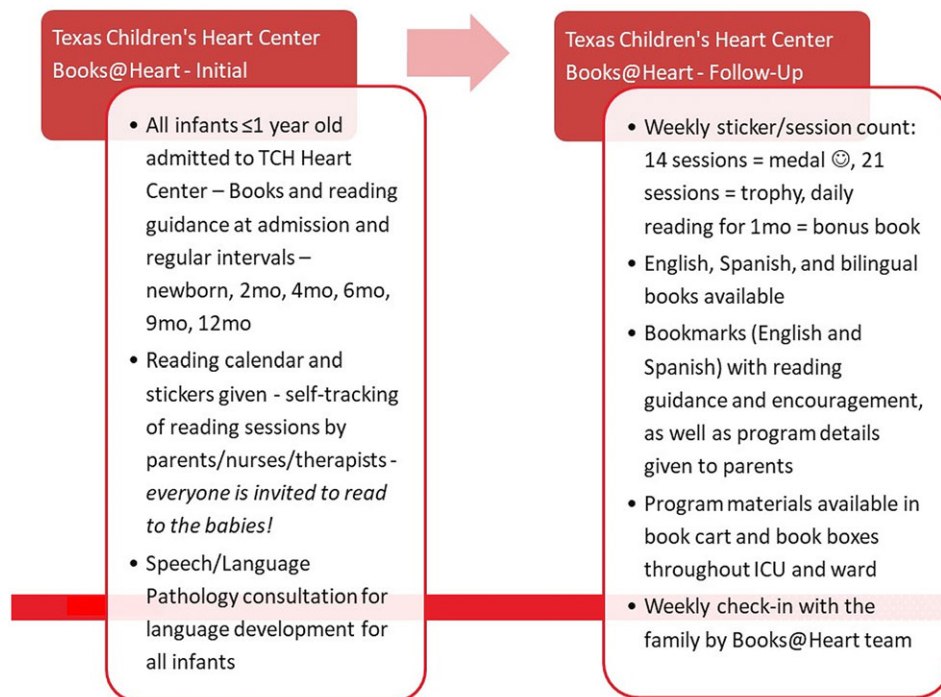


Figure 1. Overview of the process of identifying, engaging, and following up with patients and their families throughout hospital admission.

Results

Breadth of programme

From February 1, 2021, to November 1, 2023, the Books@Heart programme has provided 1,293 books to 840 infants and their families. The median age of first encounter to engage the family to provide the first book is 1.5 months (IQR 0.2–5 months). Based on family reporting, participating patients have been read to 12,901 times and received 387 reading medals, 242 reading trophies, and 84 bonus books as reading rewards.

Reading practices and access to books (Table 1)

From the initial offering of the general feedback survey (Supplemental Figure S1) in May 2021 until the most recent count on February 1, 2024, 110 survey responses were received (13% of participating families). The results are summarised in Table 1. While the majority of participating caregivers did not identify any barriers to reading to their child in the hospital (62%, 26/42), specific barriers reported included not being aware that reading was permitted and being worried about interfering with medical care.

Caregivers reported a significantly higher reading frequency after learning about Books@Heart ($p = 0.003$), with the proportion of caregivers reading to their child daily increasing from 27% (20/73) to 62% (45/73). There was also a significant improvement in access to books ($p < 0.001$) with the proportion reporting no books at home decreased from 24% (18/75) before Books@Heart to 11% (8/75) afterwards.

Programme feedback and family hospital experience (Tables 1 and 2)

A majority of caregivers reported being very satisfied or satisfied with the information and books received through Books@Heart

(93%, 50/54). All responding caregivers strongly agreed or agreed that reading helped them feel more involved in their child's care (100%, 30/30), and 95% (19/20) of respondents felt that Books@Heart improved their inpatient experience.

Of 40 survey respondents to the prospective survey (Supplemental Figure S2), caregivers' favourite aspects of reading to their child included helping them develop (85%, 34/40), that it was a normal activity (53%, 21/40) the child enjoyed (45%, 18/40), and that it helped to create a routine (40%, 16/40). They reported seeing their child more alert while reading (53%, 21/40) and perceived his or her breathing as calmer (35%, 14/40). When asked about their ability to achieve the levels of Maslow's proposed hierarchy of needs (Supplemental Figure S2, Question 4), caregivers reported feeling a sense of personal fulfillment (60%, 24/40), self-confidence (30%, 12/40), connection (98%, 39/40), and personal well-being (40%, 16/40) while reading to their child (Figure 2).

Of 58 free-form survey comments to the retrospective feedback survey (Supplemental Figure S1, Question 10 and Supplemental Figure S3), an exploratory analysis identified themes of overall satisfaction with the programme (29%) and access to books (37%) through the programme. Caregivers also expressed interest in receiving a variety of multicultural books (23%). Of 26 free-form comments to the prospective survey (Supplemental Figure S2), a second exploratory analysis identified themes of reading associated with family connection through voice, creating a break in the day, calming interactions between parents and children, and enjoyment of reading for parents (Table 3).

Discussion

To the best of our knowledge, this is the first report of the implementation of an inpatient early childhood literacy programme as a part of inpatient developmental care in a referral

Table 1. Results of QR code survey eliciting general program feedback (Supplemental Figure S1, n = 110)

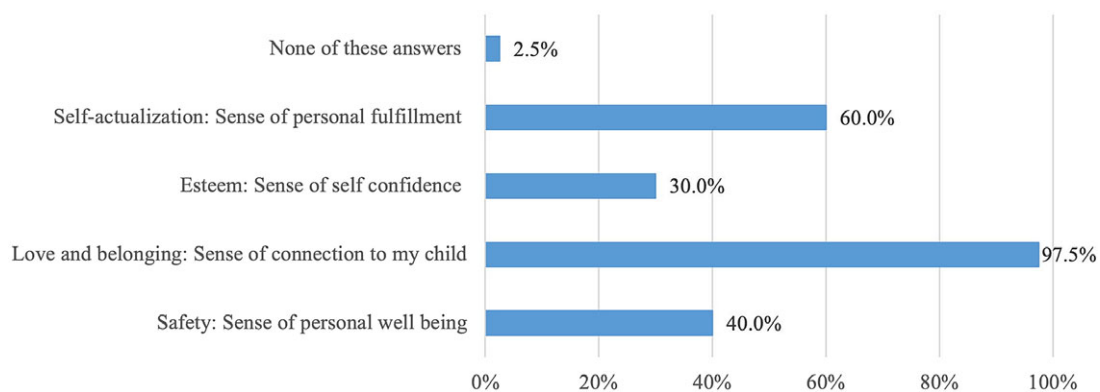
Question	No. of responses	Responses					p-value
Do you prefer English or Spanish?	n = 99	English	Spanish				
		86% (85)	14% (14)				
Are you satisfied with the type of books and information you received through Books@Heart?	n = 54	Very satisfied	Somewhat satisfied	Unsure			
		84% (45)	9% (5)	7% (4)			
Have there been any barriers to reading to your child in the hospital?	n = 42	No barriers	I'm worried I'm in the way of medical care	There is never enough time	Didn't know I was allowed to read	I do not have books to read to them	
		62% (26)	5% (2)	14% (6)	9% (4)	9% (4)	
Do you agree with the following statements?		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
Reading to my child helps me feel more connected and involved in their care	n = 30	83% (25)	17% (5)	0% (0)	0% (0)	0% (0)	
Books@Heart has improved the patient experience at Texas Children's Hospital	n = 20	60% (12)	35% (7)	5% (1)	0% (0)	0% (0)	
On average, how many times did you read to your child?		Never	A few times a month	1–2 times a week	3–5 times a week	Daily	p = 0.003
Before Books@Heart	n = 73	16% (12)	7% (5)	32% (23)	18% (13)	27% (20)	
After Books@Heart	n = 73	0% (0)	5% (4)	11% (8)	22% (16)	62% (45)	
How many books did you have for your child at home/in the hospital?		None	1–5 books	5–10 books	Too many to count		p < 0.001
Before Books@Heart	n = 75	24% (18)	31% (23)	20% (15)	25% (19)		
After Books@Heart	n = 75	11% (8)	37% (28)	20% (15)	32% (24)		

Table 2. Results of prospective survey assessing family hospital experience (Supplemental Figure S2, n = 40)

Question	Responses						
How do you feel about reading to your child while he or she is admitted to the Heart Center?	I do not enjoy it at all	I dislike it	I neither like nor dislike it	I enjoy it	I enjoy it a lot	I love it	
	0% (0)	0% (0)	0% (0)	20% (8)	22.5% (9)	57.5% (23)	
What are your favorite things about reading to your child while he or she is admitted to the Heart Center?	The stories	The way it makes me feel relaxed, happy, or entertained	That it is something normal to do with my child	That my child seems to like it	That I am helping my child develop	That it helps create a routine	
	25% (10)	37.5% (15)	52.5% (21)	45% (18)	85% (34)	40% (16)	
Which of the following changes do you see in your child when you read to him or her?	The heart rate decreases	The heart rate increases	The breathing is calmer	The breathing is more agitated	My child becomes more alert or interactive	My child becomes more relaxed or sleepy	My child interacts or plays with the book
	5% (2)	2.5% (1)	35% (14)	2.5% (1)	52.5% (21)	27.5% (11)	30% (12)
When you read to your child, which of the following feelings do you experience?	Sense of personal well being	Sense of connection to my child	Sense of self confidence	Sense of personal fulfillment	None of these answers		
	40% (16)	97.5% (39)	30% (12)	60% (24)	2.5% (1)		

Table 3. Selected quotes from caregivers demonstrating recurrent survey response themes

Theme	Quotes
Breaks in the day	“It’s nice to have something to break up the day especially when you cannot do “normal” things ie, walks, library, etc.”
Calming interactions	“When we read, he is asleep since he is a baby but he wakes up for a few moments and looks at us with a tranquility that makes us very happy.”
Connection through voice	“I think it’s particularly helpful for brand new parents who may not feel comfortable talking to a tiny baby all day - especially in a hospital setting.” “Gives me a way of interacting with him when I could not hold or comfort him.”
Enjoyment of reading	“We really enjoyed it! Reading both books provided and ones we brought ourselves.”

**Figure 2.** An inpatient early childhood literacy program helps families achieve the top four levels of Maslow’s proposed hierarchy of needs. Bars represent percentage of caregivers’ responses to “When you read to your child, which of the following feelings do you experience?” (Supplemental Figure S2, Question 4). Respondents are able to select multiple answers (n = 40).

paediatric heart centre. We found that this intervention addresses barriers to reading, increases reading frequency, improves access to books, and engages and offers support to caregivers during hospitalisation. Since non-modifiable medical and biologic variables only explain one-third of the variance in developmental delay in infants with CHD, heart failure, and heart transplantation,³ increasing inpatient developmental care and environmental optimisation to reduce stress and pain through targeted programmes are a vital part of optimising outcomes for these patients.^{26,29–31}

In general paediatric practice, Reach Out and Read has been extremely effective in improving access to books and reading and promoting literacy practices, in addition to improving language outcomes and addressing psychosocial barriers. The programme has also been effectively translated to the inpatient setting in the neonatal ICU with positive effects on caregiver and infant bonding and reinforcing language-rich practices.^{28,32} Books@Heart is the first early childhood literacy programme of its kind to be reported in an inpatient cardiac care centre modelled after Reach Out and Read. Similar to the outpatient initiative, the results of our surveys suggest that Books@Heart provides an enjoyable activity that engages families, decreases the number of families without access to books by 54%, and increases reading frequency by 130% among a more medically vulnerable population. The programme also addresses commonly cited barriers to shared reading, such as an overwhelming environment, competing responsibilities, and misunderstandings about developmentally appropriate activities,

by providing caregivers with anticipatory guidance, accessible reading resources, and support staff.¹⁷ Additionally, Books@Heart and reading were encouraged to families by bedside staff and providers on the primary care team, which further promoted this developmental care practice. This resulted in the majority of participants not citing any barriers to reading. Finally, our results suggest the programme provides a sense of normalcy among the majority of caregivers and facilitates the creation of routines that support reading in an unconventional setting among 40% of families. Although this study reports on a smaller sample size and the program’s sustainability and effects on long-term developmental outcomes have yet to be studied, the strong historical data from an outpatient setting suggest that these long-term effects may similarly translate.

Parents of infants with CHD often describe feelings of stress, fear, frustration, and guilt, particularly regarding alterations to the parent role in the hospital setting,^{33,34} which are further risk factors for developmental delay in their children with CHD.² Our study shows that the Books@Heart programme directly addresses these concerns by providing a normalising activity that promotes connection between 98% of caregivers and children, allows 100% of caregivers to feel engaged their child’s care, and improves inpatient experience for 95% of caregivers. Applying the principles of Maslow’s proposed hierarchy of needs, engaging in activities promoted by Books@Heart helps a majority of caregivers achieve the basic needs of love and belonging and self-actualisation with additional caregivers also experiencing safety and esteem.²⁷ In

turn, this may allow parents to feel they are increasingly able to maximise their potential as caregivers by participating in the programme. While this study did not directly measure parental stress, a focus on literacy-rich environments in the neonatal ICU has been shown to result in parental impressions of a sense of hope and empowerment, reduced parental stress, and enhanced bonding.³⁵ In a cardiac care unit, it has been demonstrated that parent-focused psychosocial interventions that promote maternal adjustment and family bonding decrease parental worry and anxiety and contribute to positive child outcomes, including feeding and neurodevelopment.³⁶ Improving the caregiver experience during hospitalisations has also been shown to improve patient-reported outcome measures, a growing priority for healthcare systems to improve the quality of care.³⁷ To our knowledge, this is the first inpatient reading programme that reports the effect of interventions on family hospital experience.

While we were reassured that a majority of families did not encounter barriers to reading in the hospital, it was notable that families who did report them were worried that reading to their child would interfere with his or her medical care or that there was not enough time. This suggests a need for medical team education to encourage families to read to their child. Additionally, some families also reported not being aware that they were allowed to read or that they did not have books to read. This underscores the need for ongoing medical team involvement in the implementation of this programme so that all families may feel equipped and supported to take advantage of it.

Our study carries the limitations of a single-centre report, the retrospective and self-reported nature of the survey methodology of Survey 1 carrying recall bias, and the low survey response rate. At this time, we do not have information on the long-term language and cognitive outcomes of the patients receiving this program's benefits. As the workflow of the programme involves counselling of the family member at the bedside, we could not confirm if both parents and all caregivers of a patient received the reading guidance. We presumed all parents were literate, did not assess their reading abilities, and programme materials were only available in English and Spanish. We did not have a way to control for reduced reading exposure for infants whose families were from out of town and hence less frequently at the bedside. However, our general practice was to encourage all care team members, including medical caregivers, to read to the infants. This, in addition to the partnership with reading volunteers, aimed to reduce these last two disparities. Our reading frequency counts depend on the bedside reading calendars, which are sometimes lost in room transfers as the patients move through the hospital. This systems issue was addressed by nursing education to facilitate calendar transfer during routine room changes, as well as weekly check ins and counts to reduce the number of 'lost' days without a reading calendar.

In conclusion, Books@Heart is the first reported inpatient early childhood literacy programme in a heart centre, aiming to foster the benefits of early childhood literacy such as language/cognitive development and parent-child interactions in an inpatient setting for infants with heart disease. Our study shows that Books@Heart is a feasible, well-received intervention in a heart centre and is effective in improving access to books and self-reported reading frequency. Caregiver involvement in this programme also contributed to an improved hospital experience and facilitated psychologically enriching activities, as evidenced by reported fulfillment of four of the five needs in Maslow's hierarchy, namely safety, belongingness, esteem, and self-actualisation. Families of

infants with heart disease felt more engaged with their child's care, offering an antidote to the feeling of disempowerment during admissions.

As the programme continues, future research directions include assessing the impact of an inpatient early childhood literacy programme on sustained reading practices after discharge, long-term cognitive and language outcomes, and the effect of the programme on caregiver mental health. Utilisation of existing shared learning networks such as the Cardiac Neurodevelopmental Outcome Collaborative may be helpful in investigating the feasibility and reproducibility of the impact of such a programme in other centres.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951124026702>.

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Competing interests. None.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (please name) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the Baylor College of Medicine Institutional Review Board.

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