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Evaluation of a Patient Navigation Program for Vulnerable Families

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Master of Public Health Candidate, 2019

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Abstract

Objectives: Low-income and minority children experience worse health outcomes for reasons that are complex and multifactorial. The aims of this study were to examine the experiences of caregivers and providers who participated in a patient navigation program designed to address these disparities, and to understand how the program was impactful to participants.

Methods: As part of a larger pilot-stage intervention, we conducted a qualitative study using a modified Realist Evaluation approach. Between April and October 2018, we conducted semi-structured interviews of a group of caregivers who were enrolled in the intervention, and the providers who cared for these children. Each set of interviews was thematically coded according to the realist framework categories of context, mechanism and outcome.

Results: We interviewed 50 caregivers and 23 providers, and found the program both feasible to implement and acceptable to participants. Through analysis of these interviews, we identified five mechanisms central to the program's effect. These essential components were (1) emotional support, (2) the guide serving as a liaison or information conduit, (3) facilitating communication, (4) addressing basic needs and (5) increasing familiarity with hospital environment. We developed two program theories, one for the way in which caregivers experienced the program and another for the way in which it was experienced by providers.

Conclusions: This study provided insight into mechanisms that power pediatric patient navigation programs, provided detail on which program elements were effective for families and how a program of supportive care like this one impacts provider attitudes and actions on an inpatient general medicine service.

Introduction

Low-income and minority families experience worse outcomes in the healthcare system, including in hospital environments, for reasons that are complex and multifactorial^{1,2}. Yet, few interventions exist to improve hospital outcomes for these children and their families, despite hospital stay being a potentially powerful point of intervention.

Patient navigation is a patient-centered approach to aid delivery of health care services originally developed to support cancer care among the poor³. The term now refers to programs that aim to reduce healthcare disparities by helping patients overcome barriers to care, understand different care options, make connections between providers, and make decisions surrounding treatment⁴. Patient navigation was founded upon the assumption that good care is within reach, but that low-income/minority members of the population face greater barriers to access and utilization than others. Historically, the barriers that patient navigation initially sought to address were related to the cultural competency of care; financial, communication and information access as well as fear, distrust and emotional challenges³, in addition to barriers related to navigating the medical system as a whole. Patient navigation has the potential to help families of vulnerable children overcome barriers to good care in the hospital setting by targeting poverty, differences in culture, and issues related to trust and satisfaction in the health system. Today, patient navigators provide a variety of services in areas beyond cancer care and can be deeply integrated within the health system offering strong connections to nursing, social work and related hospital services⁵. Patient navigation has been shown to be

effective in supporting care for chronic conditions⁶ but has not been fully explored in areas outside of cancer care⁶, in abbreviated forms, or extensively in pediatric settings.

Consequently, we developed a targeted inpatient patient navigation program for low-income minority children: The Family Bridge Program. Pilot-tested over a 6-month time period in 2018 to assess acceptability and feasibility, program structure was informed by a previous prospective survey conducted at Seattle Children's Hospital to identify modifiable barriers between low-income/minority status and hospital outcomes, as well as focus groups, and multi-stakeholder design workshops. To address these disparities in outcomes, we paired families with a navigator based on demographic characteristics rather than a specific diagnosis as has been the current practice^{3,5}. This paper evaluates the impact of the Family Bridge Program, and the role of the navigator (the Family Bridge Guide), and how enrolled patients and providers were influenced. Interventions focused on reducing health disparities across racial and socioeconomic status regardless of diagnosis are infrequently examined in terms of processes, thus understanding whether or not the intervention works, as well as the mechanisms at work within each intervention is important to inform future initiatives⁷. The objectives of this study were to (1) understand the experiences of caregivers and providers who interacted with the Family Bridge Program, and (2) to test and refine a program theory for an inpatient-focused patient navigation program by exploring the relationships between family contexts, program mechanisms, and family-centered outcomes.

Methods

Family Bridge Program/Setting

Seattle Children's Hospital in Seattle, Washington is a free-standing quaternary care children's hospital that serves the Pacific Northwest region of the United States, as the pediatric academic medical center for the Washington, Alaska, Montana and Idaho catchment areas. The Family Bridge Program at Seattle Children's sought to use patient navigation to address basic human needs, create a supportive care environment, and increase knowledge and skills related to the health of the child and the system as a whole for low-income and minority families admitted to the general medicine service. The program was developed over the course of 4 years with extensive input from caregivers, providers, staff, researchers, administrators, and hospital leaders.

The Family Bridge Program design was guided by Fishbein's Integrated Model of Behavior Prediction⁸, which states that actions in health care settings are changed by taking into account beliefs and expectations regarding care and equipping individuals with skills to inform those future actions can lead higher expectations and better care; and the MUSIQ theory², a theory of quality improvement that considers how the context of an intervention affects outcomes.

Program components included screening for concrete needs (including but not limited to food, transportation and housing), provision of emotional support, collection of communication preferences, assessment of the family's understanding of the current situation and practicing of strategies for communicating with the medical team, hospital and room orientation, and providing necessary connections between the hospital/health system and community

resources. Additionally, follow-up calls were placed by the Family Bridge Guide two to three days post-discharge to assist with any needs that had arisen since leaving the hospital. Program activities were offered to each enrolled family by the Family Bridge Guide, who was hired and trained for this role.

Participants and Recruitment

Caregivers were consented and enrolled prior to the initiation/delivery of any program activities or elements, and screening was conducted through the hospital electronic medical record. Eligible families included those whose child was admitted to a resident-staffed general medicine service within the past three days; whose preferred language for care was English, Spanish, or Somali; had public/no insurance; and who reported any combination of race/ethnicity besides non-Hispanic white. These families were approached in their hospital room for enrollment by the Family Bridge Guide. The enrollment period lasted from 4.16.18 to 9.21.18. The goal of this pilot study was to enroll 60 families, a number consistent with guidelines of Stage 1b pilot interventions¹⁰. Of those 60 families enrolled, all received at least one program component and 50 completed all follow-up data collection which consisted of a survey via telephone or online, followed by a telephone qualitative interview. Providers and staff who had cared for a family enrolled in the Family Bridge Program were also invited to enroll in the study. Participation included completion of a brief online survey and/or a telephone interview.

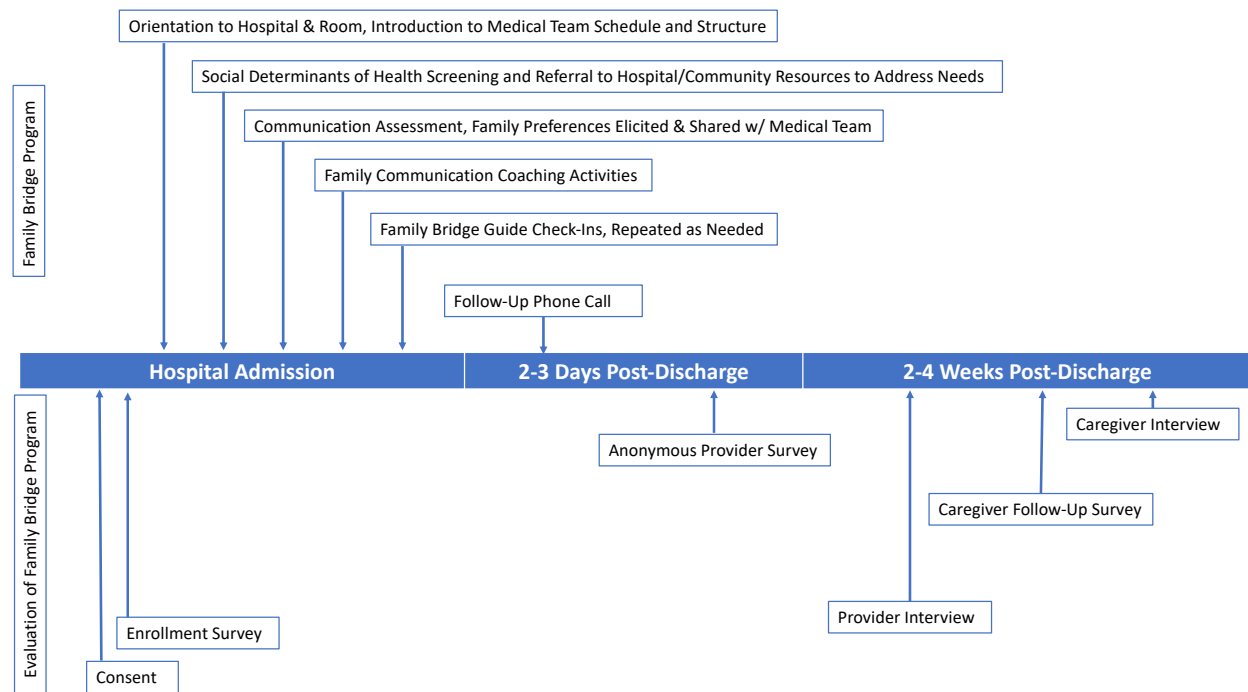


FIGURE 1. Timeline of Data Collection Activities

Legend: This figure represents the timeline of data collection activities and program elements within the time frame around a child's hospital stay.

Data Collection

Two to four weeks post-discharge we contacted families/caregivers via their preferred communication method (phone or email) to complete a follow-up questionnaire which reassessed baseline measures and unmet need for navigation. Two weeks later, we invited caregivers to participate in a semi-structured interview regarding their experience with the Family Bridge Program(see appendix for guide). Caregiver participants were compensated with a \$20 gift card for completion of the follow-up survey, and another \$20 gift card for completion of the follow-up semi-structured interview. Clinicians whose patients participated in the study were also invited to complete an online survey within 3 days of patient discharge, and/or to provide feedback via a monthly semi-structured phone interview. In this semi-structured interview, we asked providers how they perceived the program and how it impacted their work (see appendix for guide). Both interview guides were drafted and reviewed by study team

members using themes from previous focus groups with caregivers of recently hospitalized children. The results of both caregiver and provider questionnaires will be reported elsewhere, and content of both sets of interviews was analyzed for the purposes of this paper.

Caregiver interviews (n=50) were conducted from 5.31.18 to 10.21.18, and generally lasted 20-40 minutes. Most were via telephone, although several were conducted in-person to coincide with a follow-up appointment or repeat hospitalization. They were conducted in the caregiver's preferred language for care, audio-recorded, and transcribed. Provider interviews (n= 23) were conducted from 5.24.18 to 10.1.18, over the telephone. Interviews generally lasted 10-30 minutes. Detailed notes were taken during the interview, with verbatim quotes when possible. All de-identified transcripts were uploaded into Dedoose (version 8.1.21) for analysis.

Analytic Framework

Interviews were analyzed using a modified realist evaluation framework to better understand existing contexts and which program components produced reported outcomes. Realist evaluation attempts to take into account the social contexts in which humans function¹¹, and given the multi-faceted nature of the program as well as the variety of experiences that families bring to clinical encounters, this approach helped clarify why and how the program worked or did not work for each family. Realist evaluation is theory-based, and thus seeks to test the underlying program theories by asking the question: 'What works for whom in what circumstances and in what respects, and how?'¹¹ The framework divides observations into three categories: context, which describes backgrounds and circumstances which influence how the

program is received; mechanisms, which represent delivery of program components; and outcomes, which are the results of the mechanisms, given presence of a specific context.

Data Analysis

Provider and caregiver interviews were qualitatively analyzed as separate data sets to better understand the experiences of families whose children were enrolled in the program, as well as the clinicians whose patients participated. Among the caregiver group, we sought to understand how the program impacted participants, and among the clinician group how it impacted practice and team functioning, as well as how the providers perceived the impact on the caregivers.

Codebook development for caregiver interview analysis consisted of reviewing English and Spanish language transcripts and listing observed themes in each collection of transcripts. These themes were then consolidated to create a preliminary codebook. This codebook was constructed using the realist evaluation categories of context, mechanism, and outcome, and each code was discussed extensively by the team in bi-weekly meetings until agreement on meaning and definition was reached. Code testing consisted of team members blind coding 1-2 transcripts which were then discussed in team meetings. During this phase, the codebook was adjusted as needed based on team discussion. Once agreement was reached on code application to the transcripts, formal coding began and weekly meetings were held to discuss recently-coded transcripts and highlight potential issues in coding. During this phase, codes

were occasionally added or condensed. Changes were recorded and review of previously-coded transcripts was conducted to ensure that code application was consistent across the data set.

To ensure equal distribution of pairs of coding teams, the first half of the transcripts were double coded and assigned specifically to individuals to ensure that one team of coders coded no more than half of the interviews in each language. This was carried out in three phases punctuated by review of coded transcripts to scan for systematic issues. For the remaining half, it was determined that adequate agreement of coding practices had been reached thus interviews were single coded by four research team members. Spanish language excerpts for each code were reviewed and summarized by one team member and English language by another. Coding memos were written by one member (HC), and reviewed and discussed by the team as a whole. Changes were incorporated based on team opinions and further review of excerpts.

To develop the codebook for provider interviews, transcripts were reviewed and a preliminary set of main themes were developed. Themes were separated into three categories: program component, perceived impact on caregiver and perceived effect on provider to capture the division between observations made by the providers about how the program affected their work and perception of how the program impacted caregiver's experiences. Two research team members then applied codes to one transcript, and came together to discuss. Upon reaching a preliminary understanding of code application, five transcripts were coded by each coder to ensure applicability of codes across multiple transcripts. This resulted in refinement of

the codebook, and condensing of codes. And previously coded materials were reviewed to ensure that application remained consistent across the data set. Ultimately, all transcripts were double-coded. Reconciliation consisted reviewing half of the transcripts line-by-line, discussing discrepancies and recoding as necessary in real-time. Common discrepancies were compiled and the remaining transcripts were reconciled by one team member.

For both caregiver and provider interviews, coding memos were used to map connections between reported contexts, mechanisms and outcomes. Program theory diagrams were iterated upon by the team during weekly meetings using the same process as for the codebook and memos.

Results

Caregiver Interviews

Of the 60 families who were enrolled, 50 (83%) completed the follow-up interview. 66% identified as Hispanic, 24% as non-Hispanic Black and 10% as Other (Includes Native Hawaiian/Alaska Native, Asian and American Indian). Preferred language for care was predominantly English (60%), followed by Spanish (36%), and Somali (4%). More than half of respondents reported an annual family income of <\$30,000, and all children of all enrolled caregivers were insured by Medicaid.

Given what we identified through recurring themes and application of the realist framework, we developed a working theory for participant experience in Family Bridge Program. The contexts, mechanisms and outcomes that helped us to accomplish this are detailed below.

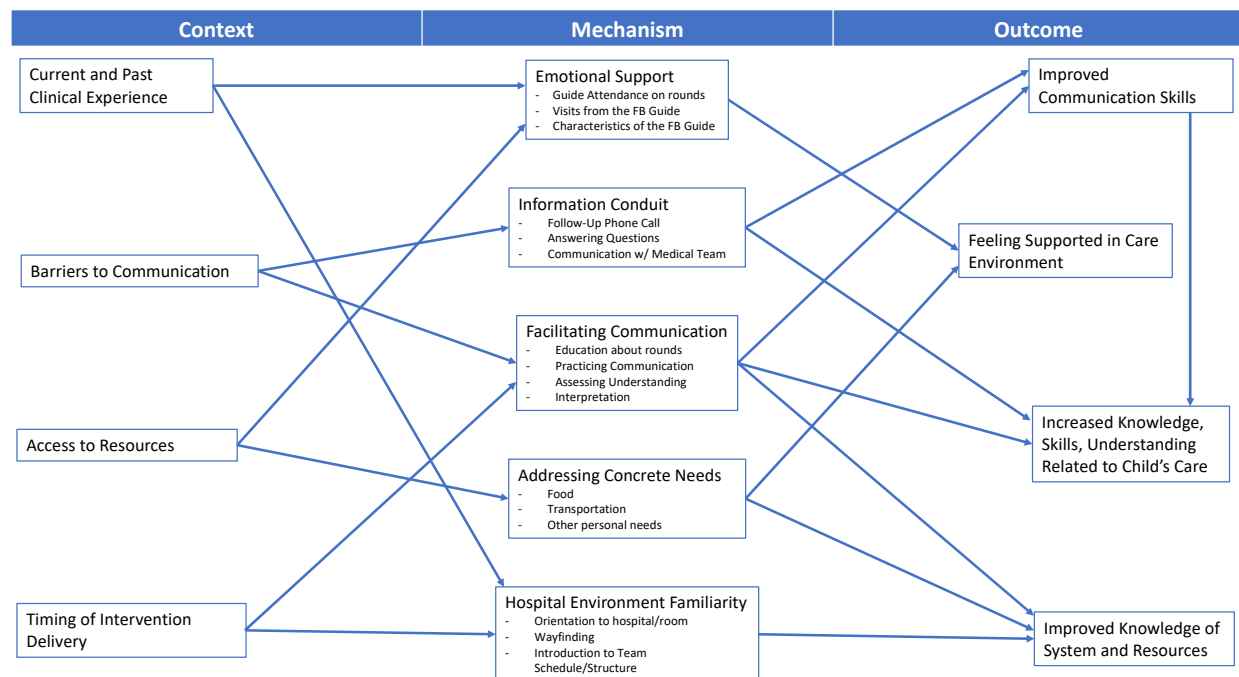


FIGURE 2. Caregiver Program Theory

Legend: This figure describes the program theory developed from interviews of enrolled caregivers. Arrows represent a relationship between a context that rendered a mechanism relevant for families, and the reported outcome associated with that mechanism. This diagram depicts only the ways in which caregivers reported that the program did work, not the ways in which it did not.

Low-income and minority families entered our program with a range of experience in clinical settings, different barriers to communication, differences in access to resources, and all received the intervention at different times within the course of their hospital stay; these varied contexts influence how program mechanisms impacted each family, and which outcomes resulted. The above figure represents the program theory that we developed from these relationships.

Contexts

We identified four contexts that influenced how the intervention was experienced by families.

These include *current and past clinical experience*, which details how familiar or unfamiliar a family may be with the health system as well as their trust in the system as a whole; *barriers to communication*, which encompasses the language, cultural and professional barriers that patients reported feeling when conversing with physicians; *access to resources*, which highlights emotional, physical or financial need; and the *timing of intervention delivery* which details when in the course of the hospital stay the family received the intervention which captures how differences in timing impacted usage of program elements and outcomes.

Current and Past Clinical Experience

Families enrolled in the program entered with differing levels of hospital familiarity and experience in the medical/health care system. These experiences impacted the way that the intervention was received, as some caregivers had established ways in which they were used to communicating with the medical team or had prior experiences that informed their approach to clinical interactions. Families who invoked current or past clinical experience also mentioned how the guide was a helpful resource, as opposed to previous experiences where they figured out the workings of the system on their own, or were unaware of available resources. Several families commented on having been in the hospital many times without knowing what types of resources were available to them. Two families mentioned that given a context of distrust in the medical staff based on events earlier in their current hospital stay, it was especially helpful to have someone available to mediate the conversation between the family and the medical

team. In these circumstances, families reported that the guide shared patient/caregiver concerns with the medical team, and the guide emphasized to the family that it was ok to speak up with concerns and that it wouldn't jeopardize the care provided to her child.

Barriers to Communication

Communication barriers of various types were reported by families. These included language barriers, barriers due to the terminology that doctors used or because of the perceived doctor/patient power differential, as well as barriers due to other cultural differences between doctors and patients. When this context was cited, families found the presence of the guide on rounds to be helpful given they couldn't always understand medical terminology (regardless of language spoken). Instances where the guide served as an intermediary by gathering information, either from support services or the medical team, was also useful to families in that it ensured that caregiver's questions were answered. Additionally, caregivers reported that the time spent by the guide showing them how to use the interpreter services and ask questions of the medical team was especially helpful and would be useful in future encounters. Caregivers also reported that the guide helped to build their confidence in what they had to say about their child's condition, which helped to combat shyness. Several caregivers cited how familiar and easy conversations with the guide were, and how this was especially helpful given the context of professional barriers that caregivers felt between themselves and the medical staff. They recalled that the guide felt like a friend or relative, and was trustworthy, as well as non-judgmental.

Access to Resources

Across many interviews, families expressed lack of access to various resources including but not limited to financial resources, social support and material goods. Many families reported coming to the hospital without necessities such as clothes and toiletries and were financially constrained thus unable to buy food in the hospital or purchase needed items. Alternatively, some families stated that they either had all that they need or lived close enough to home to be able to get what they needed. Regardless of need, caregivers recall the guide offering food, introducing them to the resources that they were eligible for, and how helpful this was during a stressful time. Some families also cited lack of social support in the hospital setting when a partner or close companion wasn't able to be present. In these situations, the guide served as an important companion to caregivers by sitting with them, and talking to them.

Timing of Intervention Delivery

Families reported varying amounts of time to use the resources provided as part of the Family Bridge Program. While all families were enrolled within three days of admittance to the general medicine service, per intervention protocol, some families had been transferred from other units and thus had already been in the hospital for many days while other families might have been enrolled on the day of discharge. Timing of intervention was specifically important for families who reported being admitted on a weekend, but not enrolled until Monday. These caregivers suggested that they may have benefited from some help over the weekend, with things ranging from ordering food to addressing concrete needs. Generally, short stays and enrollment later in the stay resulted in reports of not needing or using all of the elements of the

program. One of the most common suggestions from caregivers was to offer connection to the guide at admission.

Mechanisms

Within the realist framework theory, whether or not mechanisms trigger outcomes is based on an individual's prior experience, or context. In this model, mechanisms are composed of program components and grouped based on how families reported encountering the intervention. The groupings we observed were those of the guide providing *emotional support*, which included presence on family centered rounds, personality characteristics of the guide as observed by families, and visits from the guide while the family was inpatient; *information conduit/guide as liaison* represents the ways in which the guide gathered information for families and served as a direct connection with the doctors and medical system; *facilitating communication* which summarized the ways in which the guide helped the family to communicate with the medical team by sharing communication techniques and encouraging/practicing such communication; *addressing concrete needs* which refers to basic needs addressed and resources that the guide connected families with; finally, *familiarity with hospital environment* describes how the guide oriented families to their hospital environment by sharing knowledge and introducing to the services and resources available to them during their hospital stay.

Emotional Support

The guide was universally liked by families that she worked with, and many enthusiastically praised both her work and her mannerisms. Families remembered her as kind, supportive,

helpful, respectful, friendly, dedicated, and available to help with any concern or worry. She was also seen as respectful of personal space and seemed to understand that caregivers were going through a lot in the hospital already. Some caregivers recalled that the guide was available to attend rounds, which some families found helpful, and others declined as they felt they did not need the assistance. Families reported that the guide visited frequently, and on a specific schedule so that they always knew when to expect her. Visit frequency ranged from 3-4 visits per day to once a day, and caregivers generally reported that visits varied based on what they were dealing with and how much the family indicated that they wanted the guide's presence. Almost all caregivers endorsed that she visited enough when asked by the interviewer. On these visits, she would come by to ask about any concerns, generally check in and share the timing of rounds, and ensure that they had food to eat. During these visits, caregivers also reported that she offered social/emotional support, particularly by spending time with those who were alone at the hospital with their child or expressed a need for additional support.

Information Conduit

In many instances, caregivers report the guide served as a conduit for information between the family and the hospital services as well as the medical team. This included inquiries about available services and resources for the families, as well as asking questions of the medical team on behalf of the family regarding a child's care. Families recalled that this helped to improve communication by creating a channel for clarifying things said by the medical team, sharing frustrations, and also increasing families' awareness of services that they were eligible

for thus expanding the opportunities for assistance. Caregivers endorsed that the guide answered all of the questions caregivers asked and always helped to clarify information as needed, however there were a few things that were outside of her scope (specifically regarding durable medical equipment and specific housing needs) that a family reported she was not ultimately able to assist with, but provided websites and other information to assist their search. Many families, regardless of hospital experience, said that the guide offered more support at the hospital than they had ever received. The guide communicated with the family in a variety of ways: in person, via text message, or phone. In addition to gathering information, the guide also ensured connection to other hospital and supportive services. Another way caregivers reported the guide serving as an information conduit was in the follow-up call, post-discharge. Several families said the guide reminded them about their appointments and paperwork, and answered some questions, another reported help with filling a prescription and another received help making an appointment.

Facilitating Communication

Caregivers described various ways the guide helped them communicate, which included serving as an interpreter, practicing communication techniques, and helping families consider which questions to ask ahead of rounds or a meeting with the medical team. Caregivers reported that the guide helped clarify family understanding of clinical situations, reminded caregivers that the medical team was there to answer questions, and continuously encouraged families to not be shy. Ways that families described the guide helping them to communicate include (1) teaching them how to ask questions, (2) helping families determine questions to ask and when to ask them, and (3) showing families how to write down questions ahead of time. Many families

remarked that although they had been in the hospital previously, these communication techniques were not something had been taught before and would be helpful for future clinical encounters. This program mechanism was not needed when caregivers reported feeling comfortable asking questions of doctors, nurses and hospital staff and also during shorter reported hospital stays as families did not have time to employ their learnings.

Addressing Concrete Needs

Work done by the guide to connect families to hospital and community resources to address basic needs was remembered positively by caregivers. Caregivers reported the guide assisting with connection to various hospital resources as well as provision of food, transportation assistance, and connection to the hospital's Family Resource Center for showers, laundry, entertainment and other amenities. This included help with small items such as toothbrushes, phone chargers, toys and snacks; as well as much larger things like immigration and housing concerns, assistance with daycare enrollment, and direction to places where a caregiver might obtain their GED. With these immediate needs satisfied, several caregivers reported feelings of relief and many were surprised by the breadth of services offered at the hospital – many also expressed that they were not aware of this despite prior visits to the hospital. Many caregivers spoke to the practicality of receiving food assistance and were very grateful to have been made aware of that resource. However, not all families accepted these supportive resources – some cited simply not needing the help, while others lived close to the hospital and were able to go home periodically. Overall, families recalled actions taken by the guide to address needs as being helpful by increasing both awareness and usability of resources.

Familiarity with Hospital Environment

Caregivers reported that the orientation provided by the guide served to share information with families about the hospital environment as well as the structure of the medical team that would be providing care. Caregivers reported that this included information about when the teams would round and what to expect during rounds. Families appreciated learning how to navigate the building, and being made aware of where different services were located. This included knowing where to get coffee and do laundry, or how to travel to other floors for appointments or to go to the pharmacy. Caregivers endorsed receiving this information and recalled the descriptions given during the guide's initial orientation as an accurate reflection of daily life in the hospital. However, for shorter hospital stays or when the guide met families later on in their stay, families had either learned to navigate already or did not have enough time left in the stay to use the skills and information learned.

Outcomes

Outcomes described by caregivers as a result of program participation include *improved communication*, which encompassed ways in which families describe their communication with the medical team improving; *increased knowledge, skills and understanding related to child's care* which referred to the knowledge and skills gained by caregivers as participation in the Family Bridge Program; *improved knowledge of system and resources* which summarized the increased awareness of resources available; and *feeling supported in care environment* which referred to the positive emotional experiences reported by families as a result of program

activities. These summarize what parents reported gaining from participation in the Family Bridge Program, and the following paragraphs detail which contexts preceded the outcome, as well as which program mechanisms may have supported this result.

Improved Communication Skills

Caregivers describe being taught by the guide how to ask questions of the doctors and medical team, being reminded to write things down on a whiteboard or notepad ahead of rounds, generally speak up with concerns, and ask for an interpreter or paperwork in another language when needed. Families reported that this was helpful to increasing and improving communication between the family and the medical team. Evidence of this improvement included reports of caregivers feeling more prepared for rounds and being able to confidently express concerns and obtain answers to questions. Even among one parent/child team with extensive hospital experience, and a good understanding of rounds, their care plan, and familiarity with Children's, it was reported that the guide's assistance helped to increase and improve communication with a new doctor and through a new diagnosis.

Feeling Supported in Care Environment

Caregivers reported feeling supported by the guide directly and indirectly both in the hospital environment as a whole and in specific interactions with the medical team. As recalled by caregivers, it was helpful and appreciated when the guide checked in with families and spent time with them. Caregivers reported that she was always available should anything be needed. Specific actions aside from answering questions that contributed to feeling supported were (1)

help with wayfinding (around the hospital), (2) using the interpreter services, (3) assistance with ordering food and getting coffee, (4) filling out forms, (5) finding the pharmacy, and (6) simply serving as emotional support by keeping families company during stressful periods. Families said that they felt they had someone to contact at the hospital who could help with a broad range of needs. Several families remarked that she helped them realize that they needed help, and exactly what they needed help with; others remarked that they had never received such comprehensive help before.

Increased Knowledge, Skills, Understanding Related to Child's Care

Caregivers recall enhanced understanding of the child's current medical condition, much of which was prompted by the guide explaining or clarifying information shared by the doctors. Some caregivers, given the context of a language barrier, found the presence of the guide particularly helpful for this reason. Activities recalled by caregivers to enhance understanding around a child's care also included helping caregivers to look up information about conditions, and providing additional information. Several caregivers reported receiving help with paperwork or reminders about follow-up appointments, which was helpful given the chaotic nature of having a child in the hospital and the multitude of information and paperwork that is provided during a stay.

Improved Knowledge of System and Resources

Caregivers reported gaining knowledge about how the health system works from participation in the Family Bridge Program. This included but was not limited to knowing when rounds would

occur, and better understanding the hierarchy of the medical team and structure within a teaching hospital, knowing how to get around the hospital, and how to contact clinics and other services for follow-up. Caregivers reported being able to ask better questions, and coming to understand that the staff and services were there to help them. Increased comfort in the hospital as a result of knowing about the resources and services that they were eligible for was also reported by caregivers, who also expressed appreciation for having someone there to help them through the process. Many families, regardless of previous medical experience, found this guidance and information helpful and stated that they would use it in future health system encounters.

Suggestions for Improvement - Caregivers

The majority of families reported no suggestions for improvement and reiterated having liked everything about the program. However, the most frequent suggestion was to connect with the guide earlier in the hospital stay, rather than a few days in, as caregivers said that it would have been helpful to know about available resources as early as possible. Other suggestions included targeting resources to siblings and all family members, especially for those who travel long distances to the hospital; providing a recording of conversations; and connecting with families in outpatient clinics.

Provider Interviews

We next summarize the second set of interviews with providers and staff whose patients were enrolled in the Family Bridge Program. Twenty-three providers completed our semi-structured

interview, and of those who completed, 70% were Attending Physicians. Other roles of interviewees included medical trainees, nurses, and social workers. Participants who had multiple patients enroll in the program were invited to give feedback once during every four-week period.

In this set of interviews, providers recounted what they learned from the program as individuals, as well as how they perceived that the program impacted the caregivers of patients enrolled. We coded provider responses to understand which elements of the program were or were not acceptable to providers, and to understand how the involvement of the guide and the information that she shared changed the way that providers interacted with their patients, as well as to identify elements of the program that might be improved in future iterations or that were not acceptable to providers.

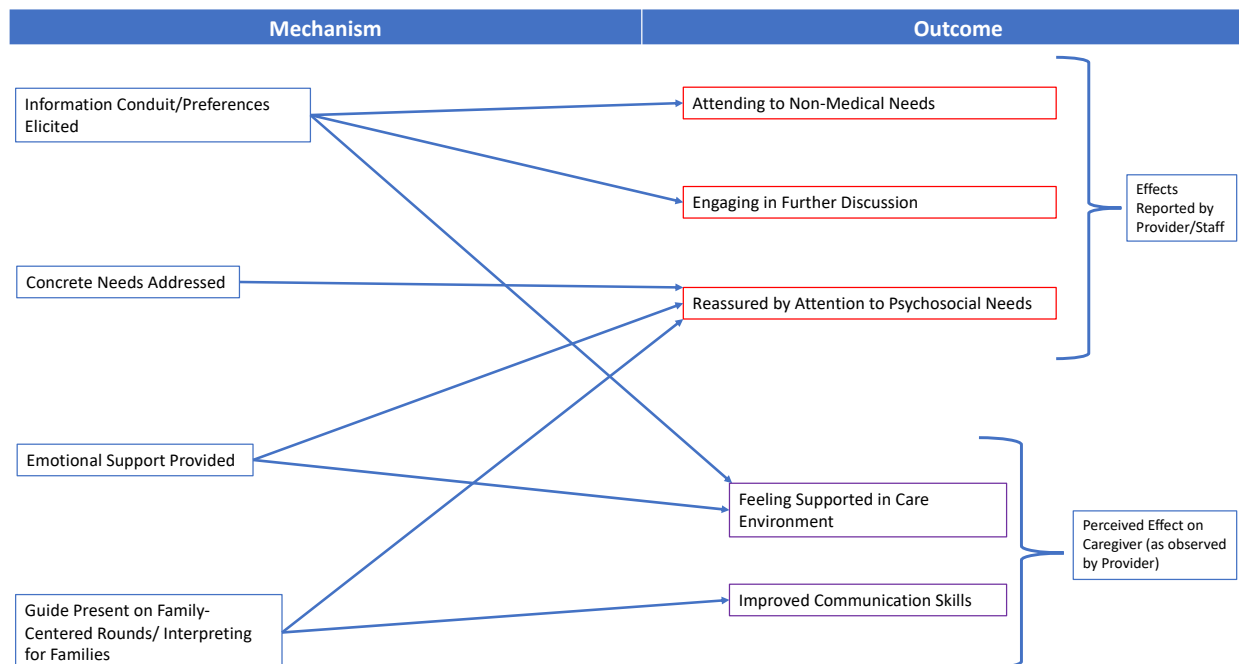


FIGURE 3. Provider Program Theory

Legend: This figure represents the reactions to program elements as described by providers, and their perception of how the same program elements impacted caregivers.

Providers interacted with the Family Bridge Program in different capacities given their roles, and within the contexts of each of their patients. As a result, providers saw many sides of the program and it impacted each provider differently. The above figure attempts to capture these relationships between mechanism and outcome, and also demonstrates the ways in which providers report being affected by participation as well as the ways in which they thought it impacted enrolled caregivers.

Mechanisms

Providers recalled four ways in which they observed the Family Bridge Program impact the caregivers of their patients, and their own practice. These were *Information Conduit/Preferences Elicited*, which details how the guide communicated with families; *Concrete Needs Addressed*, which includes ways in which the guide satisfied the basic needs of families; *Emotional Support Provided*, which represents the ways in which the guide provided emotional support to caregivers/families; and *Guide present on Family-centered rounds/Interpreting for Families*, which highlights the provider reports of the guide interpreting and participating in rounds. These mechanisms are discussed in detail below.

Information Conduit/ Preferences Elicited

Providers reported that the guide was able to spend time with families to ask questions about basic human needs, and elicit information about communication preferences and goals for

care. This information, shared with the team via email, provided opportunities to better tailor care, teaching and treatment, as well as manage expectations. Providers also reported that this offered detail that providers didn't have time to gather within a busy schedule. Some providers said that it made them remember that the family was focused on issues other than what they, as a provider, were focused on. Providers recalled that they are thinking about medications, risks and diagnoses while caregivers are worried about transportation and logistics (among other things). Additionally, providers reported that the guide was able to serve as liaison between the family and the medical team, which helped to elevate concerns and increase communication between parties. This helped the medical team know what they were doing well, and where improvements could be made.

Concrete Needs Addressed

Providers appreciated that someone was proactively screening for and addressing identified basic human needs, and saw the benefits of having someone help families to advocate for themselves. In the view of providers, this intervention highlighted social determinants that the medical team would ultimately uncover, but wouldn't become aware of immediately. It was acknowledged that while the nurses nominally screen for food security, it's not as intentional or communicated as widely as it was in the Family Bridge Program. Providers also reported that knowing the information helped them feel closer to their patients and start the process of getting to know them better, and the information shared from the assessment included facts providers hadn't thought about or might not have considered. The emails offered practical advice as to what had been done, and what should be done which providers reported helped to

understand how this might fit into workflow. Members of the medical team also shared that having an awareness of family needs helped to plan for a smooth discharge in a few specific cases, as this gave them advanced notice in terms of challenges to expect and additional supports that the hospital could provide to make the transition home easier.

Emotional Support Provided

In the eyes of the providers, the guide helped families navigate through complex social or medical moments by bonding with both caregivers and children and spending time with families that providers simply didn't have to give. Additionally, providers saw the guide as an important presence on rounds, creating a good dynamic and not only being a 'parental cheerleader' but also ensuring that caregiver's questions were answered fully by the medical team. With more complex social or medical cases, providers said that the guide's involvement helped the medical team understand what more they might be doing to support a family. The advocacy and communication skills taught to caregivers were noticed by providers, who also mentioned that caregivers seemed to feel supported by the guide's presence on rounds.

Guide Present on Family-Centered Rounds and Interpreting for Families

Providers reported that the guide provided interpretation services for families, and attended rounds to help bridge communication gaps and ensure that caregivers were respected and attended to. In the view of providers, the guide generally served as an advocate for the caregiver and family. This was especially helpful when specialists were involved and when the diagnosis was complex, both to help translate medical jargon and ensure that the family was

aware of the goals of care. Additionally, providers expressed that they often observed that some families were reluctant to accept or ask for an interpreter – the family bridge program offered a solution to this, and may remove some of the stigma associated with requesting an interpreter.

Outcomes

In the provider interviews, we asked about both the effect of the Family Bridge Program on providers, as well as the ways in which they thought it affected the caregivers of their patients. Thus, the outcomes category of the provider interviews is split into two sub-categories, one that summarizes the reported effects on providers, and another focused on the perceived effect on caregivers. Effects reported by provider/staff include reports of the provider *attending to non-medical needs*, which suggests consideration of elements beyond the strictly medical; *engaging in further discussion*, when the provider returned to the family for further discussion given an issue raised by the guide; and being *reassured by attention to psychosocial needs*, which details when providers expressed feelings of comfort related to knowing that someone was caring for the emotional health of their patients. Perceived effect on caregiver (as observed by provider) includes the outcomes of *feeling supported in care environment*, which captures the social support provided by the guide that providers witnessed; and *improved communication*, which includes provider reports of improvements that they saw in communication between the parent and the medical team.

Effects Reported by Providers/Staff

Attending to Non-Medical Needs

Providers reported that evaluations provided by the guide served as important reminders to attend to the social and emotional needs of the patient and their family; and were grateful that their patients were being connected to services to address issues such as food security, as well as offer support for needs related to transportation, housing and insurance coverage. This outcome also captures the realization expressed by some providers of the differences in focus areas between caregivers and providers, and how this gap might be bridged to offer better support to the family and ultimately better care to the child.

Engaging in Further Discussion

Providers recalled that evaluations shared by the guide specifically helped the medical team know when to return to the family for further conversation or to ensure full understanding. Providers also recalled that learning the communication preferences of the family encouraged them to consider their usual patterns of interaction with patients, and how these might be tailored to better fit each family's needs and preferences. Providers acknowledged that the guide's evaluation called attention to things that nurses and doctors may be missing, and by alerting them to this gap in understanding providers were held accountable and given the opportunity go back and address concerns raised. An example given was the simplification of a 50-page teaching package into a 1-page teaching tool to help a family better understand their child's condition, which was done after a member of the medical team noticed the family's preferences regarding learning style as well as their educational background. Providers recall

being nudged to stop and think about the information presented to them in the guide's emails, and in many cases reported returning to a family to clarify.

Reassured by Attention to Psychosocial Needs

The Family Bridge Program provided a service that the medical team wished they had time to provide, as reported by providers. Several acknowledged that it was helpful to have someone embedded in the care team structure whose explicit goal was to focus on connecting a family to services and ensure that their educational and psychosocial needs were attended to. The program, providers reported, collected in-depth information that would not otherwise have been available. They recalled that having this information clearly presented also helped to distribute workload – especially among nurses or social workers, and in instances where tasks were not clearly defined. Providers reported that this information also helped gauge how they were doing in terms of communicating with the family, and what could be done better. Especially in complicated clinical circumstances, this was seen as beneficial.

Perceived Effect on Caregiver (as reported by Provider)

Feeling Supported in Care Environment

In the eyes of providers, the guide's presence on rounds and in the patient's room helped caregivers to speak up by letting them know that their concerns are valid and providing accompaniment and emotional support. Additionally, by tending to the emotional needs of a family and connecting with them in a way that the providers were not able to do as a result of

other duties, time constraints, and professional barriers, it was reported that the guide helped providers by supporting their work and attending to the psychosocial needs.

Improved Communication Skills

Providers reported noticing the improved confidence that some caregivers had in the presence of the guide. Additionally, by interpreting for families and also participating in rounds the guide helped to bridge some social and emotional gaps for families. In the eyes of providers, the guide helped parents to remember that they did have important things to say about the child's care and reminded the clinical team that information from parents was valuable and important to tailoring overall care.

Suggestions for Improvement - Providers

Suggestions for program improvement from providers were often focused on how information was shared with the clinical team, and ways that the increased communication could be incorporated into already-busy workflows. Given reported differences in communication habits while on service or during a daily shift, clinical personnel had differing opinions regarding how information elicited by the guide should be relayed and recorded. This included discussion of the best point of contact (attending, resident, or nurse) and what mode of communication was used (pager, email, electronic medical record, or face-to-face communication). Providers expressed that their preferred communication method would be in-person, although they recognized that a standing meeting or even a conversation mandate would not be possible or ideal in a hospital setting. Respondents also shared ideas related to increasing awareness

around the Family Bridge Program internally, as many providers were not aware of the pilot study (despite efforts of the research team) until their patients were enrolled. These suggestions included a profile on the hospital's internal site, and visits to nursing staff meetings. Other suggestions included further integration with services currently offered, initiating program screening and enrollment registration to ensure that the family is supported throughout their hospital stay. This final suggestion was notable because it mirrored feedback from caregivers regarding what improvements they would like to see in the program.

Discussion

Application of a modified realist approach helped us to understand whether or not this patient navigation program worked for low-income, minority children and their families to improve hospital outcomes; which circumstances or contexts influenced the impact of this program; and how program mechanisms may have led to outcomes reported by providers and caregivers. This analysis suggests that the Family Bridge Program was both feasible and acceptable to providers and caregivers. Individuals reported that information and skills shared by the guide and the guide's companionship in the hospital setting were helpful in both encouraging advocacy among parents and emotionally supporting them. The guide was also valued for sharing detailed knowledge of the patient with providers, which encouraged more holistic care for each family. In our study, participants identified five mechanisms of action central to the program's effect. These essential components were (1) emotional support, (2) serving as a liaison or information conduit, (3) facilitating communication, (4) addressing basic needs and (5) increasing familiarity with hospital environment.

First, emotional support (1), while seen as a central component of our patient navigation intervention, has not been prioritized or thoroughly discussed in the existing academic literature. Dohan & Schrag's qualitative study of patient navigation found that programs that catered to patients with a language barrier also frequently provided social and emotional support¹², however the interpersonal component of most patient navigation programs today focus more on individual barrier reduction rather than emotional support¹³. That said, this may be an issue of terminology as within the cancer literature patient navigators are described to have worked with patients focusing on the fear and feelings associated with cancer¹³. This suggests that the underlying theme of emotional support in patient navigation may not be well discussed, particularly given the challenges associated with quantifying such programmatic elements. In our analysis, a deeper understanding of the mechanisms of action that drive emotional support to be effective adds to the literature with regards to how the patient navigation process works for families in the pediatric setting.

Moving to our second item, the concept of a patient navigator as an information conduit (2) is well-represented in the literature. Qualitative analysis of previous patient navigation programs demonstrated that the navigator frequently took on tasks related to clarifying information, and liaising between the patient and the medical team¹². In other studies, the patient navigator has been identified as a point person between teams, and crucial to the flow of communication and information¹⁴. However, an environmental scan of pediatric patient navigation programs in Canada saw only six of the programs surveyed in which the navigator was part of an

interdisciplinary team¹⁵. In our intervention, the guide occupied the traditional navigator space by serving as a liaison or conduit of information, while also working within an interdisciplinary team to relay information and ensure that care the provided was the most comprehensive that it could be.

Representation of a patient navigator as a facilitator of communication (3), was also important in other patient navigation interventions. Especially in programs that aim to address barriers related to language and culture, this was relatively common¹². However, in the same aforementioned review of Canadian pediatric navigation programs, it was stated that most programs did not place an emphasis on empowerment and advocacy¹⁵. This is where our program differs, as this was a key programmatic activity and one that both caregivers and clinicians commented on. This represents one of the ways in which the Family Bridge Program has the potential to reduce disparities in care across racial and socioeconomic lines: our results are supported by past studies in the health disparities literature that suggest improvements in communication lead to improved health outcomes¹⁶, and others that suggest doctors employ more patient-centered methods with patients who they perceive are better communicators¹⁷.

On addressing basic needs (4), a literature review shows that increasing access or connection to community and hospital resources is also a common characteristic of programs in the in cancer patient navigation literature¹³. In one study, when navigators helped with tasks that were not directly related to supporting the diagnostic evaluation – such as logistics, and addressing needs for resources – there was a positive correlation with more timely diagnosis¹⁸. In offering

support to families, we hope to ease the burden of having a child in the hospital, and provide space for caregivers to not only support their children but also care for themselves.

Finally, the last mechanism of action identified by participants was familiarity with hospital environment (5). Given the paucity of literature examining patient navigation, and even fewer interventions focused on the hospital environment, it's unsurprising that we did not see wayfinding in hospitals highlighted in many other interventions. One intervention focused on introducing rural populations in Nepal to care at a district hospital, and as part of patient navigation efforts included extensive mapping and education around the buildings to ease comfort at the facility¹⁹. Similarly, in our intervention, caregivers reported that wayfinding was a helpful mechanism especially for families with less experience in the hospital or the health system, and early on in the stay, thus this might be prioritized for families with lower identified familiarity with the system.

Having discussed the existing empirical literature regarding our five key mechanisms, we turn now to broader observation of the field. Since patient navigation was developed and piloted more than two decades ago, it has been expanded and applied in myriad settings. Generally poorly defined in the literature, patient navigation has been implemented in many different variations without being standardized^{12,13,23}. Further, the exploration of patient navigation processes and intervention mechanisms lags far behind the field itself. While a few studies describe how the patient navigation experience and process helps to improve cancer screening and follow-up in underserved settings²⁰, in diabetes care²¹, and in previously-incarcerated

persons²², an understanding of how the mechanism of patient navigation works in pediatric settings has not been fully developed in the United States. Some initiatives in Canada give us clues as to how these programs might function¹⁵, but the vast differences between the American and Canadian health systems make the comparison challenging. This modified realist evaluation adds to the literature by providing detail on how navigation programs function in pediatric settings, how they can be improved, and how the experience of being enrolled in the program influenced both providers and caregivers. A cross-sectional study recently surveyed patient navigators in the United States to better understand which populations they were working with, as well as how their time was spent. This study identified five key tasks of patient navigators: These were (1) basic navigation, (2) arrangement and referrals to services, (3) care coordination, (4) treatment support and (5) clinical trials/peer support⁵. While the categorization is different, these tasks are suggestive of our mechanisms of access to resources and facilitating communication, and prior qualitative research suggests the work of patient navigators should be specific to the needs of the populations served¹². Our qualitative analysis suggests that an abbreviated intervention, such as the Family Bridge Program, can provide benefits to families that will influence their health outcomes and provide supports specific to both the pediatric setting and non-disease specific navigation assignment.

We also observed important culturally mediated program responses that are important to note. While caregivers were universally positive in their recounts of participation in the Family Bridge Program, Spanish-speaking caregivers were notably less critical and more complimentary. We hypothesize that this difference could be due to a number of factors. These include the fact

that the navigator was also Hispanic, and thus cultural congruence played a role. While congruence is being measured and tested as part of the Patient Navigation Research Program (PNRP)¹³, there is not a wealth of supporting information to suggest that this observation could be attributed to congruence alone. However, a prior study demonstrated a tendency among Spanish-speaking populations to utilize scales differently and to report outcomes more positively than others despite absence of differences in care, which may also have contributed to our results²⁵. Other studies have shown that Spanish-speaking families in clinical settings often do not feel empowered to request interpretation, and preferred a live interpreter/Spanish speaking provider ²⁶. Since this program offered both interpretation and navigation to families, it may have been providing access to additional services to Spanish-speaking families (relative to English-speaking families) that they wouldn't have received otherwise.

Other notable aspects of our program include that two specific outcomes observed by the providers which were the same as those reported by the caregivers: feeling supported in care environment, and improved communication. This suggests alignment and shared experience among participating groups. Differences between provider and caregiver reports were greatest in attention paid to the presence of the guide on rounds. While this was discussed in caregiver accounts of their experience, providers saw the guide's presence as a strength and an important source of emotional support for parents in the intervention.

Next, and importantly, it was observed that the utility of program components was impacted by the point during a hospital stay in which a family was enrolled. The earlier that the guide was able to reach and enroll families, the more that they were able to benefit from the services provided to orient to the hospital/room, address basic needs, and receive communication coaching to be used in conversations with the medical team. Families who were enrolled close to discharge reported not having time to use the resources that they were introduced to, and families enrolled later in their stay sometimes had already been assisted with basic needs or figured out their own way of getting what they needed without assistance from the program.

With these key insights in mind, takeaways for future iterations include increasing efforts to connect with families as soon as they are admitted to the hospital and specifically targeting families with little or no hospital experience. These are the families who appeared to report the most benefit from our intervention. Given that there was only one navigator, there were delays in reaching all families. Increased navigators could reduce this barrier. While both these conclusions seem intuitive, the data provided here is supportive.

Limitations of the study include the overweighting of English and Spanish-speaking families in enrollment (96%). In the provider interviews, the majority of respondents (70%) were attending physicians thus the opinions of the program from the provider side mainly represent the viewpoint of this group rather than the entirety of the SCH General Medicine staff. Additionally, given the complex hospital environment which these families are recalling, coding was done to

capture only elements of the Family Bridge Program, so an absence of comment on a certain element of hospital experience does not mean that the element itself was absent.

Conclusion

Overall, both caregivers and providers found program activities acceptable and useful. The presence of the guide was seen as helpful to caregivers in connecting to existing resources and serving as a source of emotional support. Among providers, the information that the guide elicited was helpful in providing high-quality care to the child.

This program provided insight into how pediatric patient navigation programs function, and how supportive services can be integrated into general medicine care in a way that works with clinicians' workflow and is also supportive to caregivers during their time in the hospital. Based on prior research, activities in our program that worked to improve the skills and knowledge of families who are at risk of worse outcomes, and increased empathy and awareness of context among care providers, have the potential to improve health and well-being for all involved.

Appendices & Supplements

Transcript Excerpts – Caregiver Interviews

Contexts

Current and Past Clinical Experience	So I feel like [the doctor] was trying to hurry us and get us out, instead of actually paying attention to... the needs of my daughter and being cautious with her... [the guide] was informative in...letting me know "it's ok for you to speak up, I don't know if anyone told you that but it's ok for you to speak up."
	[the guide] had told me to ask the questions that I had in plain form. You know, nothing too...[complicated] just ask them...It was my first time staying in the hospital since [my child] had been born. So [the guide] just made us more comfortable.
Barriers to Communication	[the guide] was just talking to me, making me feel comfortable – it was foreign to me. You know... [she said], don't get shy...that's the only way you can get the answer... that's the only way that they can understand... what you want...I know in some cultures it's hard... to ask questions and she was making [me] ...feel comfortable... to ask what I need
	Sometimes... the way [the doctors] understand the issue is different from the way I understand the issue because I am the caregiver not the doctor, and they are not caregivers so they ...[don't]... worry as I...worry. And I don't know what a doctor knows so we are...different
Access to Resources	[the guide] also told me about transportation and reassured me that I don't have to panic about how am I going to get home...from the hospital... that was a good thing.
	...no one really plans to go to the emergency. So, when I came...I didn't have... money on me... [in] the last minute thing you're not thinking "oh I need to go to the hospital so I need to grab my cash or my card on me so I can pay"
Timing of Intervention Delivery	Knowing that from the beginning [that needs would be addressed] would have been really, really helpful. Cause even worrying, you know, about where ...[you're] going to go get food and that kind of thing, that's pretty stressful when you're in here.
	...when we got into the hospital, just some of the information things like how to order meals, what some of the neighboring services were [wasn't clear], cause...we came on a Saturday and we left on a Monday ...we were asking the nurses where some of that information was and they were very helpful... [but]it would have been nice to have someone there in the beginning to help answer questions and make sure we were checked in ok

Mechanisms

Emotional Support	... [the guide] was really amazing, the way she was communicating with me, even the level of her voice was like very calm...she was just waiting for me to ...[find the words], ... Anybody could be comfortable around her.-...I was...more interested in...talk[ing] to her more about the program and... what I was seeing...she's very helpful, and she's very conversant, and...she took care of us.
	[the guide] wasn't overbearing...she wasn't forceful...-I just really like her attitude and just her spirit and her friendliness
Information Conduit	Well [the guide] helped me connect to other services too, and then she really made sure that like I was taken care of, like by the other hospital staff
	...[the guide] shared our concerns with the doctor and then ... the doctor came back and explained [her] thinking to help us understand...and gave us a bigger picture...
	...and when we were like "we kinda need an answer right now" [the guide] came and checked in and told us things we never knew, we had been to children's multiple times and never knew...Other people are kind [and] ...they just go but [the guide] just sat and said "we have a lot of other stuff that we offer"

Facilitating Communication	I realized...I felt confident saying it myself: '...how's my son', 'what's his condition look like', you know 'what's best for the child' ...I had a lot of things I could ...[say] when [the doctors] asked. [The doctors said], 'oh that's really interesting you ask that' and they was more interested in what I had to say – I felt like I had a lot of knowledge after all...as a mom
	... I don't think that if [the guide] hadn't said anything the doctor would have picked up on our frustration...[be]cause it was the weekend we saw so many different people...so it was nice that [the guide] heard our concerns and shared them with the appropriate people. I don't think that would have happened without [the guide].
	Whatever questions I had, [the guide] wrote them down for me. So, when the doctors came... I looked at them and then I asked...[otherwise], you have a question, and they come, and you forget
Addressing Concrete Needs	I think it's great that this program is... here. Because...it does help...to have someone kind of... help you out...and look after your needs and make sure they're met, cause it's just so chaotic when you're here, you know? Just having someone making sure that you have food, and resources, cause you just forget.
	...[the guide] gave me like a voucher for food...we were there for like 3 days and every time we've visited [Seattle Children's] no one's ever told us about...[food vouchers].
Familiarity with Hospital Environment	... [the guide] helped us with, directing us to places that we needed to go and where we could find information... [and] they helped us with giving us the menu and letting us know where we can order, the time that they open the time that they close, directing us through the number and everything

Outcomes

Improved Communication Skills	Because last year I was at the hospital, another hospital, and they d[id] not have [anything] like this program... I d[id] not know how to talk to them or how to communicate [with] the doctor.
	I wouldn't have asked ...the doctors for help...if I didn't understand, I was just kind of like 'ok ok' and [the guide] was like 'if you don't understand ...[something, it would be a good idea to ask ... [a question]' Or she would even tell the nurse then...[the nurse] would... [explain] it to me better...I told her that I understood things better by...[having] them show me, with...[a handout] how to do it. Then next time [the doctors] came they would bring papers... talking about whatever they were doing so I would understand better.
Feeling Supported in Care Environment	...I was just there with [my child] by myself, so I think ...[that was] helpful... [if] the family member is alone and there's nobody there, you know, to listen to you, or comfort you, or let you know that everything is ok, and that's what she did. [the guide] was kind of like a significant family member who was there to help me along.
Increased Knowledge, Skills, Understanding Related to Child's Care	...After we're discharged [there was] so much paperwork and I just forget [about it], but when [the guide] called, I went and looked over stuff, because I really forget...that things [we]re there...it served as a reminder...to check over stuff... there were notes on there and protocol to follow [for] her next appointment, and when it was scheduled
Improved Knowledge of System and Resources	There are things that when you go to a hospital, you don't really know cause it's not really something that you do very often. [the guide] addressed a lot of things, like help we can get, and programs we can qualify [for]...I think she covered everything. When I left the hospital, there wasn't any doubt or...something that I would have asked or something that I would've known... it was pretty clear.

Caregiver Interview Guide

Semi-Structured Interview Guide: Caregivers

Note: this was a guide, to reflect general topics to be discussed, but was not a verbatim script.

Thank you so much for having participated in the Family Bridge program. Since it was a new program, we are studying it so that we can try to make it work better for families. The purpose of this interview was to understand what you liked and didn't like about it, and how we can make it serve your needs better. I expect this call to take between 15 and 30 minutes, although

it was fine for it to take more or less depending on how much feedback you'd like to provide. Was now still a good time? If not, when could I call you again?

We will be audio recording this conversation and taking notes, so that we make sure we capture all of your thoughts and ideas. However, we will make sure we do not share any of your feedback in a way that would make your identity known. We will also not be sharing any of individual feedback directly with the Family Bridge guide, unless you ask us to, so please feel free to be totally honest.

Services received: I'd love to hear from you about what services the Family Bridge guide provided for you or helped you with.

Prompts: Did she help you get resources or services you needed? Did she help figure out what the best ways were for the medical team to communicate with you? Did she help you prepare for rounds? Did she call you after you left the hospital?

Positive aspects: What parts of the program or your interactions with the Family Bridge guide did you like? Why?

Negative aspects: What parts of the program or your interactions with the Family Bridge guide didn't you like? Why not?

Suggested change: What would you suggest to make the program better?

TNav navigator: What did you think of the person providing the Family Bridge services?

Prompts: Was she helpful? Knowledgeable? Supportive? Respectful? Did she make you feel comfortable? Anything you wish was different?

Specific feedback (to be asked for things not already mentioned by the caregiver):

Any additional things you liked or didn't like about the following:

- the orientation to the hospital provided by the Family Bridge guide?
- the way the Family Bridge guide explained the program and the study evaluating it?
- the survey questions we asked on the computer to enroll you in the study?
- helping you get connected to resources or services?
- helping to understand your communication preferences and communicate them to the medical team?
- helping to prepare you for rounds?
- checking in after you left the hospital?
- the survey questions we asked you after you left the hospital?
- how often the Family Bridge guide came by to see you?
- how easily you could get in contact with the Family Bridge guide while you were in the hospital?
- Did you feel like the questions the Family Bridge guide asked you were repetitive of questions other people were asking? If so, did that bother you?

Overall satisfaction with program: How satisfied were you with the Family Bridge program, on a scale from 1 to 5, with 1 being totally dissatisfied, 3 being neutral, and 5 being totally satisfied?

Thank you so much for your time! We really appreciate the feedback. It will help us improve the program for the future. And as a reminder, to thank you for your time, we will be sending you an additional \$20 gift card. *(Check in to make sure they have been able to use the gift card(s) without too much difficulty).*

Transcript Excerpts – Provider Interview

Mechanisms

Information Conduit/Preferences Elicited	...we [physicians] think we're doing a great job [communicating] but the family has no idea what's going on. It personally changed how I was communicating with the family, and I made sure the rest of the team was using that [information] too. It was nice that someone was getting that info [on needs] for us. We should be [getting it], but we don't.
	It was really helpful, knowing mom's primary focus and goal was to get the patient home. No unrealistic expectations...Knowing her availability, that she was ok with small discussions happening with her other daughter to interpret, but really wanted any big medical discussion to happen with an interpreter. We usually don't get that level of detail, maybe we should elicit it more. It was really being able to make our communication consistent with what mom wanted [that mattered].
Concrete Needs Addressed	I thought it was helpful that [the guide] had proactively met with families and was able to connect to a bunch of basic resources in Washington state, because this was a family the team hadn't really brought to my attention. So if [the guide] hadn't been involved, the team might never have called SW, and I think these were resources that were really helpful for the family to know about.
	[the guide] uncovered some housing insecurity and transportation needs for this family. So when we were planning discharge, it really helped us understand what would be needed to get the family home safely.
Emotional Support Provided	It was a non-ideal clinical situation, and we wanted to give more info that we had. So it was really nice to have someone taking the more holistic and thoughtful approach...there was just so much going on that the rest of us didn't have a lot of capacity to take on. It was hard to feel like we were doing a good job with them on a not-busy day, so almost impossible to do a good job on a busy day. So knowing someone else was walking this walk with them was really great.
Guide Present on Family-Centered Rounds/ Guide as Interpreter	One of the challenges in caring for LEP families is the possibility that caregivers feel reluctant to accept an interpreter from physicians, when they report a non-English preferred language of care at registration. I would love for Family Bridge language to be shared with registration and nursing, so that caregiver have heard normalizing, supportive language around interpreter use from the beginning, rather than a day into admission.
	I thought the dynamic on rounds was really great... [and] it was really great to have a parental cheerleader there on rounds.
	I liked that [the guide] was able to round with us, it made her part of the team. Even though I didn't have a direct discussion with her, the residents did, so the family really understood that we care.

Outcomes

Attending to Non-Medical Needs	We focus a lot on the medical stuff, not as much on all that background information. I am not good at doing that, I probably need to be better. So that was really helpful... just in terms of how I approached the mom, how I introduced myself... [and] I could provide [that information] for the whole team.
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	It's telling that we need the program... as an individual provider or team of providers can miss so many opportunities... my agenda may not be the same as theirs, that they may not understand the natural history that way we do...Caregivers don't know about the pathway and steroids, but they're worried about food and transportation. Its awareness regarding that [difference in focus]. It'd be my goal that we could [do] that independent of the Family Bridge team...but it's hard to know all those things, and even if we do know it, we don't necessarily pass it along to the next attending.
	It was very helpful to understand the education/literacy level of my patient's caregivers. It is not something I typically screen for directly, but I was able to consider how to be more clear in my communication and [knew] not to rely on written forms of communication.
Engaging in Further Discussion (with family)	The email... was extremely helpful and provided a lot more information that made me realize I needed to go back and talk more with the mom about the things that had been brought up with the guide.
Reassured by Attention to Psychosocial Needs	So really, really good to have that supportive help, as there was just so much going on that the rest of us didn't have a lot of capacity to take on. It was hard to feel like we were doing a good job with them on a not-busy day, so almost impossible to do a good job on a busy day. So knowing someone else was walking this walk with them was really great. So great that someone was tending to the psychosocial and communication aspects of care.
	[the guide] really bonded with the family. For me to go above and beyond means spending an extra 30 min in there, which is time I don't have. So it's really nice to know that someone is spending that time with your families.
Feeling Supported in Care Environment	I also really appreciated how much the family said they felt supported...this was a kid with a lot of cooks in the kitchen, so many specialties, but no one was really providing wrap around services and figuring out what the family needed and how they are coping. We didn't even know what we didn't know.
	I think it's really helping us function better as a team, having not a social worker, not a nurse, but someone else asking families these really important questions to make sure they get what they need. I love it.
	[one]...patient who didn't have a diagnosis, she was pretty sick, the family had a lot of social issues, they were native, not used to having a lot of doctors involved, so she really helped navigate them through the process, helped with us know how to communicate with them.
Improved Communication Skills	I found the email very helpful because it had a lot of detail about the best way to explain things and teach the family. I really liked having the guide there during rounds, she was really supportive to the family, told the mom they were good questions, and made sure that the team didn't blow any of them off—not that we would have, but you know, made sure we answered everything. The mom was maybe a little intimidated and the guide was there boosting her up.
	Dad was more empowered to tell me about a major concern when ...[the guide] was there...[also] very helpful with a dad who wanted to use English but was more comfortable in Spanish, [it] seemed like she was teaching him how to advocate for his son
	The medical student made a teaching tool for just for this family based on ...[communication preferences]. The kid has asthma and we give a 50-page teaching packet... he went through and made it a 1 page tool, using simple language, and... scheduled teaching time with them. And all the language he is using he got from [the guide]

Provider Interview Guide

Semi-Structured Interview Guide: Providers and Staff

Note: this was a guide, to reflect general topics to be discussed, but was not a verbatim script.

Thank you so much for your willingness to give us feedback on the Family Bridge program. Since it was a new program, we are studying it so that we can try to make it work better for families and medical care providers. The purpose of this interview was to understand what you liked and didn't like about it, and how we can make it better. I expect this conversation to take between 5 and 30 minutes, although it was fine for it to take more or less depending on how much feedback you'd like to provide. Was now still a good time? If not, when could I call you again? We will be audio recording this conversation and taking notes, so that we make sure we capture all of your thoughts and ideas. However, we will make sure we do not share any of your feedback in a way that would make your identity known. We will also not be sharing any of individual feedback directly with the Family Bridge guide, unless you ask us to, so please feel free to be totally honest.

Exposure: What kind of interactions have you had with the Family Bridge guide? With what frequency?

General feedback: Do you have any overall thoughts or impressions about the program?

Positive aspects: What parts of the program or your interactions with the Family Bridge guide did you like? Why? Did you find the program helpful to you, in your job?

Negative aspects: What parts of the program or your interactions with the Family Bridge guide didn't you like? Why not? Did any part of the program make your job harder?

Suggested change: Are there things we should change about the program? What would you recommend?

Family Bridge guide: What did you think of the person providing the Family Bridge services? Anything you wish was different?

Prompts: Consider the following attributes: helpfulness, knowledge, communication (clear and effective?), respectfulness

Specific feedback (to be asked for things not already mentioned by the provider):

Any additional things you liked or didn't like about the following:

- how the Family Bridge program was explained to you?
- how the Family Bridge guide communicated with you or interacted with you?
- how the Family Bridge guide interacted with families you were caring for?

Thank you so much for your time! We really appreciate the feedback. It will help us improve the program for the future!

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