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Building a prototype of a continence goal-selection tool for children with spina bifida: patient, parental and urology provider recommendations

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Summary

Introduction: No tools exist to help children with spina bifida (SB) describe their incontinence concerns and to help their providers account for them when evaluating management success. Our aim was to understand patients', parents', and clinicians' preferences about how a SB continence goal-selection tool (MyGoal-C) should look and function, and to create a tool prototype.

Methods: We used a qualitative research approach integrated with human-centered design methods. We recruited children with SB (8–17 years old), parents (>=18 years old) of children with SB (8–17 years old) in clinic and online, and urology healthcare providers at our institution. We surveyed children and parents, and conducted parent and provider Zoom-based prototyping sessions to iteratively design the app. Design researchers analyzed online activities using affinity diagramming, group analysis and modeling activities. Provider sessions were analyzed with qualitative thematic analysis based on grounded theory. Recruitment continued until saturation was reached.

Results: Thirteen children with SB participated (median age: 10 years old, 4 female, 9 shunted, 10 using bladder catheterizations). Thirty-seven parents participated (33 mothers, median age: 43 years old). Children and parents unanimously recommended an app and their comments generated 6 major theme domains: goal-setting process, in-app content, working toward goals,

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urology provider check-in, app customization, and using big data to improve future functionality. Twenty-one of the parents participated in 3 prototyping sessions with 6 breakout groups. The remaining 16 parents and 13 children then completed the Prototype Testing Survey, leading to a refined prototype and a visual flow map of the app experience (Figure). Feedback from 11 urology healthcare providers (7 female, 6 advanced practice providers) generated 8 themes: patient engagement/autonomy, clearly displaying results, integration into clinic workflow, not increasing clinical staff burden, potential clinician bias, parental involvement, limitations of the app, and future app adaptation. These cumulative data allowed for a construction of a final app prototype.

Comment: Findings of our study lay the foundation for creating a goal-selection app that meets preferences and needs of children, parents, and providers. Next steps involve building the app, testing its usability and assessing it prospectively in a clinical setting.

Conclusions: Children with SB and parents preferred an app to help them set and track continence goals. All stakeholders, including urology providers, offered complementary and mutually reinforcing feedback to guide the creation of an app prototype that would ultimately be integrated into a clinic visit.

Keywords

decision-making; pediatrics; spinal dysraphism; qualitative research; incontinence

Introduction

Most children with spina bifida (SB) experience urinary and fecal incontinence (UI and FI) [1,2]. Both of these issues are typically managed by a urologist. In addition to maintaining renal health, one of the urologist's main goals during an office visit is to identify which patients care about incontinence, to what degree they care, and what their expectations are. Unfortunately, no tools exist to help patients and healthcare providers systematically delineate patient's concerns and to subsequently take them into account when evaluating management success[3,4]. Given this knowledge gap, we set out to develop a patient-centered UI and FI continence goal-selection MyGoal-C tool for children with SB to assist in shared decision making (SDM) between patients, parents and clinicians[5].

Our recent work [5] corroborated evidence that children with SB consider UI and FI to be closely linked and to be related to self-esteem, independence, relationships and social activities[6,7]. By identifying specific continence goals affecting areas of life most important to a child, the healthcare team can help the child achieve goals with the greatest potential impact on their health-related quality of life (HRQOL). To maximize the future use of a tool by children, parents and healthcare providers, it is critical to engage them throughout the research and development process, making the intervention truly patient-centered[8]. Therefore, we collaborated with a design research team to facilitate the research process with patients, parents, researchers, and healthcare providers[9].

The current study aimed to employ a qualitative research approach integrating design methods to understand patients', parents', and clinicians' preferences about how the goal-selection tool should look, how it should function and to create a prototype. Subsequent

work will involve a quantitative evaluation of the tool focused on usability and effectiveness, including HRQOL.

Methods

Approach

We partnered with Research Jam (RJ), the Indiana Clinical and Translation Science Institutes' Patient Engagement Core, which has expertise in applying human-centered design research techniques to health services research. RJ has successfully created multiple patient-centered research interventions in the past[9–11]. Design methods augment traditional qualitative tool development, improving the understanding of people's needs by often going beyond what people themselves expect[9,12]. It ensures that the end products are “co-designed” by all stakeholders.

Participants

Children with SB (8–17 years old) living in the United States were recruited at our center's pediatric SB clinic and online through the Spina Bifida Indiana and national Spina Bifida Association, and the “Bowel Management in Spina Bifida” Facebook group. Interested children and parents recruited in clinic were contacted via telephone to discuss participation. Those recruited online read the online study information sheet. Parent/guardian participants (≥ 18 years old) whose children had SB (≥ 8 years old) were recruited similarly. Pediatric urology healthcare providers at our institution were invited by email to participate in a focus group. Children's assent and parental and provider consent were obtained online. Children and parents received \$50 for completing each study component, providers received \$20 (Institutional Review Board approval: 1707207063).

Data collection

Data collection occurred in four iterative stages: an initial online Qualtrics-based toolkit for children and parents, an online Zoom prototyping design sessions with parents, a Qualtrics-based Prototyping Testing Survey for children and parents (Online Supplement), and a focus group discussion with pediatric urology healthcare providers. Recruitment continued from July 2020 to March 2021 until thematic saturation was reached (no new themes were identified)[13].

The initial online toolkit included activities to inform the goal-setting tool messaging. Parents were invited to “Build a motivational message for your child” by selecting from a set of images and writing captions. Children were similarly invited to “Build a message to give advice to others your age with spina bifida.”

During Zoom design sessions, parents in facilitated breakout groups brainstormed ideas for and then prototyped several goal-setting tools using an online whiteboarding tool (Miro, miro.com). At the end of each session, the breakout groups came together to review and discuss the prototypes of the other groups.

Based on analysis of the design sessions, the team created visualizations of a preliminary prototype. In the Prototype Testing Survey, children and parents were shown a visual flow

map (Figure) and an overview of how the app would work. They were asked what they liked, what they would change, and what might prevent them from using it. Participants were also taken through a challenge mapping goals-setting prototype[14] to create incontinence goals. This involved several prompts with free-text answers to populate a preformatted goal phrase to yield a highly personalized goal. A refined prototype was created.

During provider Zoom sessions, urology providers were presented with a visual flow map and refined prototype. They were invited to describe how to improve it to best fit into clinic workflow, address provider preferences, and work for a variety of patient-provider encounter scenarios.

Outcomes

Our objectives were to determine the nature of the goals-selection tool, user recommendations for the tool's structure and function, and to develop a prototype to guide future tool construction.

Analysis

Content from the prototypes (which were created in Miro during the design sessions) was copied onto digital sticky notes. Deidentified content from the design session transcripts was also copied to sticky notes. Data were analyzed in Miro by 4–5 team members over four 2-hour video meetings. The team used affinity diagramming, which involved iteratively grouping notes based on similar content[15]. Headings describing their content were given to each group, later becoming themes and theme domains. Headings were reviewed and revised through group discussion.

The team brainstormed potential visual models that could be used to explore the data and externalize internal mental models emerging through the research process. Each team member received a set of sticky notes containing the headings derived from affinity diagramming and created visual models. An experience map was selected to visually represent a person's journey using the tool and to find potential improvement opportunities[16].

The pediatric urology provider discussion was audio recorded, transcribed, and iteratively analyzed based on a systematic grounded theory approach[17,18]. Since the research question focuses on describing a process involving individuals app use steps, a grounded theory approach was chosen for this study. Transcripts were used to extract and rephrase significant phrases in more general language and iteratively derive meanings to identifying subsequent independent and exhaustive themes by two coders. Separate audio recording transcript and interview codes documents were used along an alphanumeric category coding system. Discrepancies were settled by consulting the audio recordings and consensus.

Results

Child and parent population characteristics

Thirteen children participated (nine males) at a median age of 10 years old (Table 1). Parents of all children participated in the parent portion of the study. Eleven were white, nine had

shunted hydrocephalus, and six were community ambulators. Ten managed their bladder with clean intermittent catheterizations and four used a MACE/Chait tube. Thirty-seven parents participated (33 mothers) at a median age of 43 years old (Table 1). No couples participated. Thirteen parents were white. Seventeen of their children with SB were female with a median age of 15 years old. Twenty children had shunted hydrocephalus, 22 were community ambulators, 25 managed their bladder with catheterizations, and 14 used a MACE/Chait tube.

What should the goal-setting tool look?—Children and parents unanimously recommended a goals-setting smartphone app. They raised concerns that a webpage or a paper-based aid would lack the portability to accompany the patient in different settings (home, travel, trips, school, etc.), the versatility of always being at hand (for reminders, recording progress, etc.), and the adaptability to individual preferences (for customized goals, reminders, etc.).

How should the app work?—Twenty-one parents participated in three prototyping sessions (2 hours each) with six breakout groups. Another 16 parents and 13 children completed the Prototype Testing Survey. Several themes emerged from comments provided by children and parents (Table 2), leading to a visual flow map of the app experience (Figure). Emerging themes grouped into six domains briefly described here. (1) *Goal-setting process* themes included: providing goal ideas to select along with patient-generated goals, giving parents and healthcare providers input in goal-selection, goals should address the most immediate needs first, the app should generate a practical plan to achieve goals, and teaching patients goal-setting skills over time. (2) *In-app content* themes included: education, social support/tips, and resources specific to goals. (3) *Working toward goals* themes included: tracking, reminders, and rewards. Remaining domains were (4) *Urology provider check-in*, (5) *App customization*, and (6) *Using big data features to improve future functionality and recommendations*.

Parents imagining the goal-setting process

During all three co-design sessions, parents focused on implementing goals more than setting them. When asked pointedly about how a patient would determine a goal, parents suggested discussions with their doctor. Since this is not feasible in an app, we prototyped an automated goal-selection approach in the Prototype Testing Survey using modified challenge mapping. An example of a generated goal, with phrases filled out by participant in italics, was: “You will *pay close attention when I need to be cathed or have reminders, telling myself it’s not the end of the world to finish the thing*. This will help you *have less accidents* so that you *cannot waste time cleaning up accidents and changing clothes*.” The final goals created using this approach were impractical due to confusing grammar, unclear or overly complex answers, unsolvable problems (question: “how can I/my child control his/her bladder?” answer: “not possible”), trouble diverging (limited final options), and goals which were not actionable (not measurable or time-based).

Building on our earlier work[5], we selected a modifiable menu-based approach for goal-setting. Children and parents endorsed this approach in the Prototype Testing Survey

as appropriate, easy to follow, and in agreement with their recommendations to include prepopulated, but editable, goals in the app (Table 2).

Pediatric urology provider themes

Eleven healthcare professionals participated (7 females) (Table 1). All were white. Five were urologists, six were advanced practice providers. Four had more than 10 years of experience caring for children with SB (four had 5–10 years, three had <5 years). Discussion during two sessions (1.5 hours each) generated several themes:

(1) Patient engagement and autonomy.—The app may “help train patients in taking up more responsibility for their care” by collaboratively setting expectations and tracking goals. The app can facilitate communication between patients, families, and providers, allowing for more personalized therapies to be selected and tracked. Users are already familiar with a smartphone platform, making adoption easier. An in-app system of points or awards for accomplishing goals, possibly with competition between users, may optimize patient motivation. Educational content (troubleshooting common continence problems, testimonials, etc.) may help engage children and families. Collaborating with external groups or associations may facilitate this. While important, educational content should be a secondary priority while the app undergoes initial testing.

(2) Clearly displaying results.—Progress made in targeted behaviors, goal achievement and quality of life should be displayed in an easy to interpret fashion (single screen or printout) to facilitate discussion with the family. It could then be scanned into the medical record.

(3) Integration into clinic workflow.—The app should inform, rather than interfere with, work in an already busy clinic. Goal-selection should be initiated by the child and parent(s) prior to the clinic visit and finalized with the provider.

(4) App should not increase work burden on clinical staff between clinic visits.—The app should ideally improve communication with families during appointments without increasing phone calls to the office. App troubleshooting should be outsourced. Given existing modes of communication, clinicians did not support direct in-app messaging between patients and clinic staff.

(5) Minimizing clinician bias.—Periodically collecting data for subsequent review by healthcare providers may bias users to provide responses that “please the provider.” But the risk of this should be low, since the data is collected in the setting of their daily life, responses are visible to patients for real-time feedback and this approach is an extrapolation of data already collected at regular clinic visits.

(6) Acknowledging parental involvement.—Since parents will be involved in using the app, it will be difficult to separate the child’s input from their parents’. While emphasis will be on the child providing most of the information in the app, parental involvement mirrors the reality that parents are significantly engaged in the urological management of children with SB.

(7) Limitations of smartphone app.—Children without a smartphone will be unable to use the app, potentially limiting its use during school hours or by low income individuals.

(8) Adaptation and expansion of the app.—The app should be periodically updated using feedback from users. A similar app would be useful in the care of adults with SB who struggle with similar continence concerns in a more complex personal and social context. If successful, the app could be useful for non-urological SB care and other disease processes.

App prototype

Incorporating feedback from all stakeholders, a final prototype of the app was developed (Figure 1). We also developed a mockup output of tracked results which would be available for the patient, parent and the clinician to discuss during the clinic visit and incorporate in the medical record (Figure 2).

Discussion

Based on the recommendations of children with SB, parents, and urology healthcare providers, this study generated a prototype of a patient-centered continence goals-selection app. While the domains and themes we identified reflected each stakeholder group's viewpoints, virtually all of them were complementary, aiming at an app with maximal benefit and minimal burden to users. Some recommendations appeared conflicted, such as those regarding integrating the app into a clinical care. Patients and parents suggested potential additional goal-setting visits and an in-app provider chat function. Providers preferred integrating the app into existing visits and relying on existing patient/parent-provider communication. Efficiently integrating the app into the current workflow will be critical to successful implementation, especially outside the research setting.

Smartphone apps present an attractive low-cost intervention to reach a wide population to augment typical care. While the number of pediatric healthcare apps is growing, the use of this interactive mobile technology in continence goal setting is new. Many, especially early, apps pertaining to physical and mental health tend to focus on symptom reporting and did not to include goal setting or treatment content[19,20]. The next generation of clinical pediatric apps are undergoing randomized controlled testing for problems ranging from childhood obesity [21]and oral health[22], to cognitive behavioral therapy [23] and pain management in sickle cell disease[24]. Similarly, we hope the MyGoal-C app will help improve care of children with SB. To optimize future user experience and “gamification,” we anticipate further updating the MyGoal-C app based on patterns of use. This includes updating goal selection approaches based on goals actually selected and may involve adding the possibility of competing with other users, or themselves, with accumulated awards for achieved goals.

The next steps in the study involve the construction of the app, testing in the clinic and evaluating its user-friendliness, or usability [25]. While usability testing typically occurs in areas of engineering and computer-human interaction, it is only emerging in healthcare. Afterwards, we will conduct a “before-after” prospective study of a cohort of children with SB to quantitatively assess patient-reported outcomes before and after implementing the

MyGoal-C app to determine how treated UI impacts HRQOL. Recruitment for this study's "before" phase has begun. Once operationalized and prospectively validated, our hope is to make the app available to patients outside our center.

The study has several limitations. While we initially planned to rely mostly on children's input, it was not surprising that children were uninterested in sharing intimate details of UI and FI with researchers they did not know. We pivoted to engage children with online surveys and engaged parents and healthcare providers in group discussions. Despite a heterogeneous study population representing varying levels of disability and locations of urological care, parents participating were English-speaking, predominantly white mothers. We did not capture the educational level or health literacy of study participants. Despite its small size, our sample is typical of qualitative studies, and we will recruit new groups of participants in subsequent study stages. The readability level of the functional app could not be assessed since it is currently being constructed. Subsequent work will include an evaluation of any differences in app use and effectiveness based on age and sex. In the future, we hope to develop a related app for adults with SB. Importantly, we plan to periodically update and customize the app based on users' input data and feedback to continue crafting a patient-centered tool to help in clinical decision making.

Conclusions

Children with SB and parents preferred an app to help them set and track continence goals. All stakeholders, including urology providers, offered complementary and mutually reinforcing feedback to guide the creation of an app prototype integrated into the workflow of a typical clinic visit.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

UI	urinary incontinence
FI	fecal incontinence
SB	spina bifida

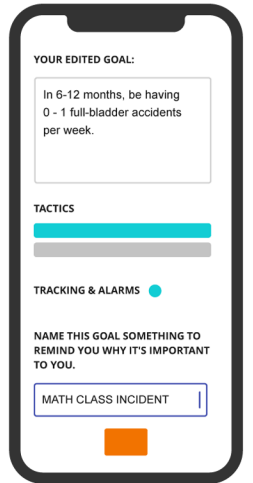
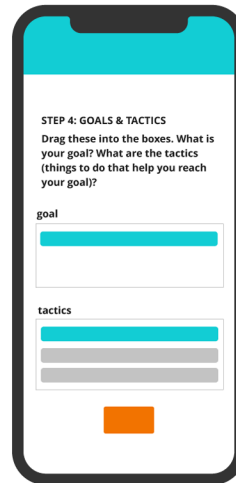
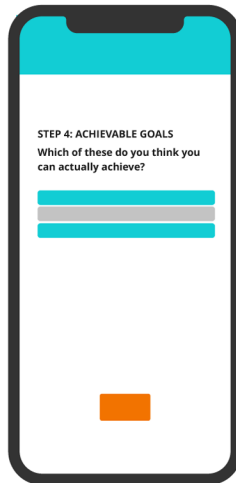
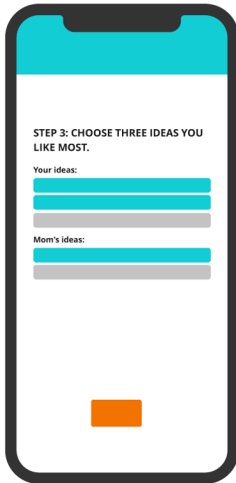
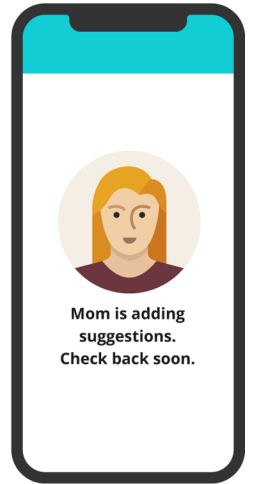
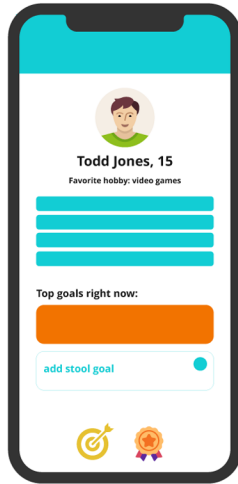
SDM	shared decision making
HRQOL	health-related quality of life
RJ	Research Jam

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AT HOME



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AT EACH APPOINTMENT

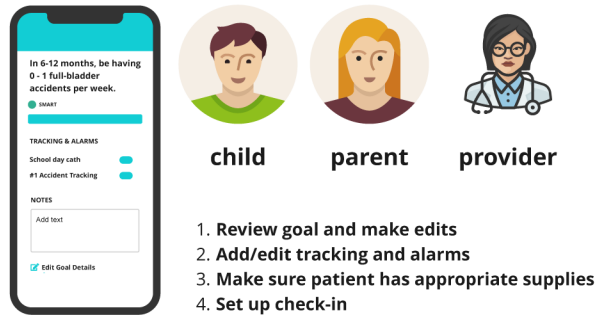


Figure 1.
Prototype of the MyGoal-C app.



TODD'S CHECK-IN REPORT - 12 MONTHS

MATH CLASS INCIDENT - ACHIEVED!

In 6-12 months, be having 0 - 1 full-bladder accidents per week.

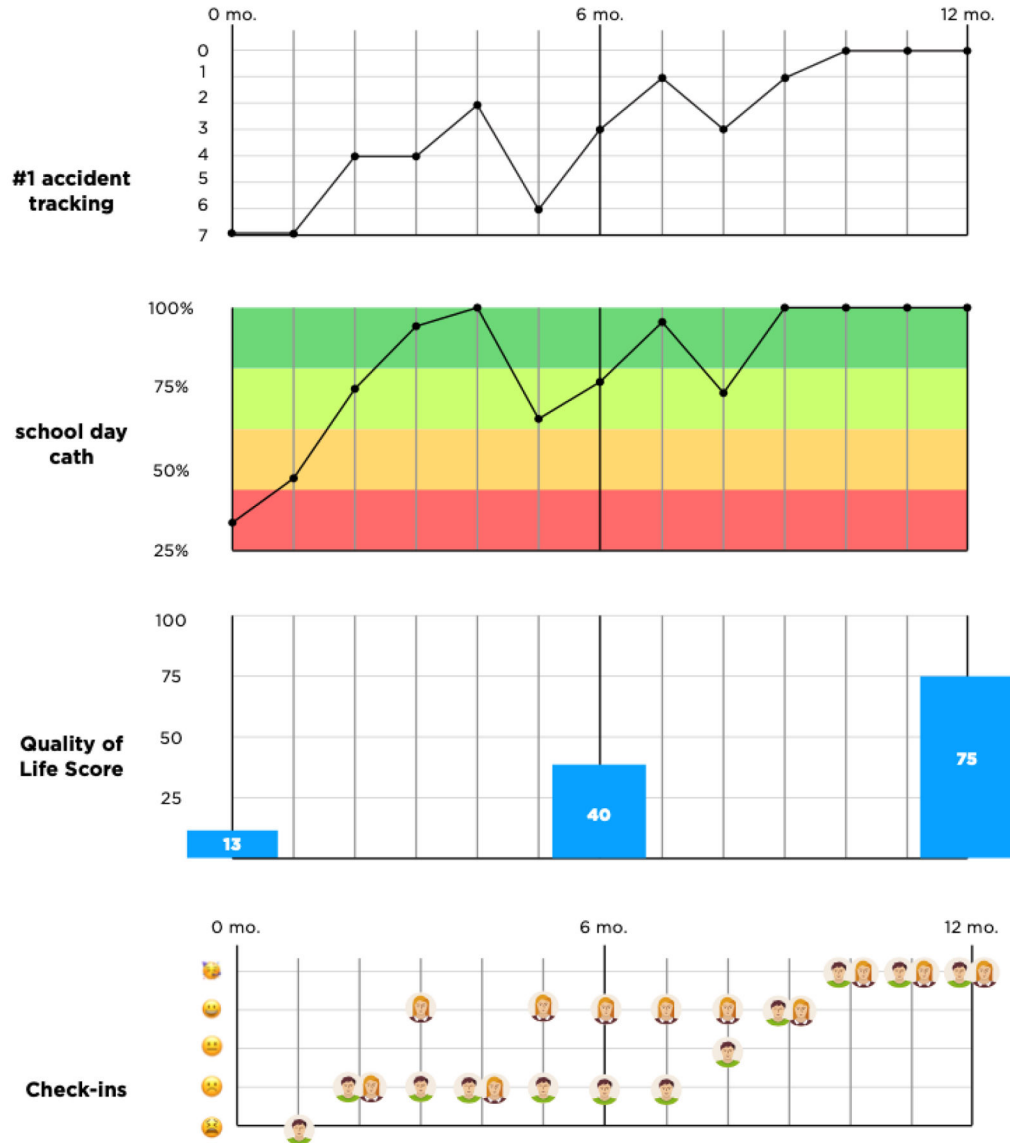


Figure 2. Mockup output of tracking results which would be available for the patient, parents, and the clinician for discussion during the clinic visit and incorporated in the medical record.

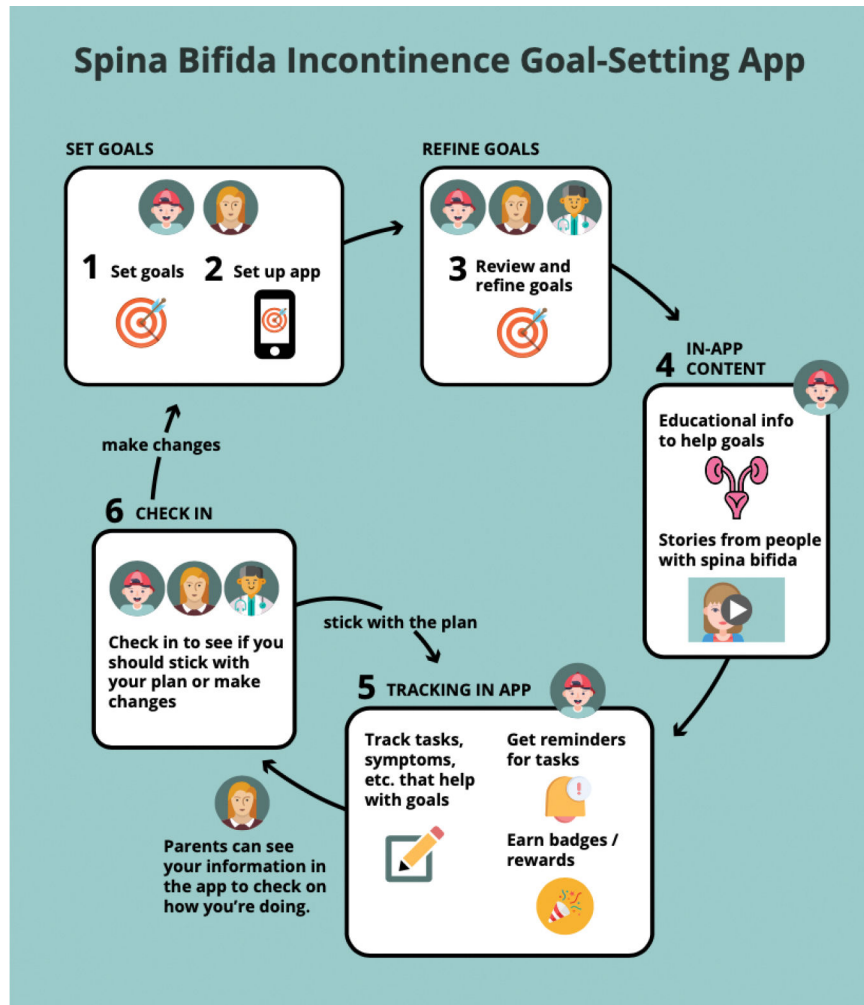


Figure.
Visual flow map of the MyGoal-C app experience.

Table 1.

Demographics of child and parent participants.

Variable	Child participants (n=13)	Parent participants (n=37)	Children of parent participants (n=37)	Healthcare professionals (n=11)
Females	2 (15%)	33 (89%) (mothers)	17 (46%)	7 (64%)
Males	9 (69%)	0 (0%) (fathers)	20 (54%)	4 (36%)
Prefer not to answer	2 (15%)	4 (11%)	0 (0%)	0 (0%)
Median age (IQR, years)	10 (9–13)	43 (37–45)	15 (12–17)	n/a
Race:	11 (85%)	13 (35%)	12 (32%)	11 (100%)
White	0 (0%)	0 (0%)	0 (0%)	0 (0%)
African American	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Native Hawaiian or Pacific Islander	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Multiracial	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Prefer not to answer	2 (15%)	24 (65%)	25 (68%)	0 (0%)
Ethnicity: Latino/a	1 (6%)	0 (0%)	0 (0%)	0 (0%)
Recruited online	7 (54%)	30 (81%)	n/a	0 (0%)
Recruited in clinic	6 (46%)	7 (19%)		11 (100%)
Shunted hydrocephalus (%)	9 (69%)	n/a	20 (54%)	n/a
Community ambulators (%)	6 (46%) 4	n/a	22 (59%)	n/a
Bladder managed with clean intermittent catheterizations (%):	10 (77%)	n/a	25 (68%)	n/a
Via stoma	5		8	
Via urethra	5		17	
Bowel management with a Malone antegrade continence enema/Chait tube (%)	4 (31%)	n/a	14 (38%)	n/a

Table 2.

Children's and parents' recommendations for continence goal-setting app

Domain	Theme	Description
Goal-setting process	Give goal ideas with patient-generated goals	<ul style="list-style-type: none"> - Some patients may not be able to come up with goals without seeing examples. - Choices may empower children but too many could be overwhelming. - Parents also suggested a "don't care" option.
	While patients should set their goals, parents should have some input	<ul style="list-style-type: none"> - Parents may offer good insights into the challenges the child faces and the context needed to achieve a goal.
	Healthcare provider should help patient set goals	<ul style="list-style-type: none"> - This discussion would best occur during an in-person appointment. - Since the clinic days are already long, some work could be done ahead of time by patients and parents (at home or waiting room) or involve a separate appointment.
	Goals should address most immediate needs first	<ul style="list-style-type: none"> - Goals should be prioritized based on the individual's diagnosis, symptoms, age, developmental stage, and lifestyle. - Patients should not be given options that will not work for their specific situation.
	Tool should create a practical plan to achieve goals	<ul style="list-style-type: none"> - Plans need to be practical. Parents and patients may need to problem-solve to make plans more actionable. - Other parents or staff might help with psychosocial issues, insurance coverage, medical trauma issues, and practical tips.
	Teach patient goal-setting skills over time	<ul style="list-style-type: none"> - The app can prepare older adolescents for making harder decisions and setting more challenging goals.
In-app content	Education	<ul style="list-style-type: none"> - Parents recommended age- and developmentally-appropriate educational components in the app (i.e., anatomy, why management tasks are important, differences between management options and patient testimonials).
	Social support	<ul style="list-style-type: none"> - Parents imagined a feature allowing parents to chat with other parents and patients to chat with other patients and a peer mentor to encourage the patient and help with issues.
	Tips and resources specific to goals	<ul style="list-style-type: none"> - Resources will help children troubleshoot issues.
Working toward goal	Tracking	<ul style="list-style-type: none"> - Patients can easily track all information and behaviors relevant to meeting their goals, including progress toward goal, successes, management tasks (catheterizations, enemas, etc.), incidents (accidents, for example), diet, emotions, urination and bowel movements.
	Reminders	<ul style="list-style-type: none"> - Parents and patients already use reminders for important tasks and some tracking systems they used were not flexible enough to meet their needs. They preferred having reminders and tracking together in one app. - Alarm fatigue was a concern.
	Rewards	<ul style="list-style-type: none"> - A reward or badge system could encourage patients to track and work toward goals, including in-app rewards (upgrades for their in-app character) or virtual points redeemable to the parent for tangible rewards in real life.
Urology provider check-in		<ul style="list-style-type: none"> - Suggested interactions with the urologist ranged from providing periodic goal-setting and tracking reports outside the app to help with future discussions about the goals to an in-app chat feature.
Customization		<ul style="list-style-type: none"> - Customizable features included an avatar, tracking and reminders.
Big data features to improve recommendations		<ul style="list-style-type: none"> - Data collected by the app should be used to improve recommendations to future users based on their specific condition and goals. The app could make suggestions based on what worked for others. - It could provide families with insights into what to look for in the future based on longer-term users. - The app could notify the provider if it detected a concerning trend in the user's data.