

**Demystifying Spina Bifida Guidelines Using a Periodicity Schedule: A Quality
Improvement Project**

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Abstract

Background: Spina bifida is a congenital neural tube defect affecting the spine, spinal cord, and brain with lifelong health-related consequences. Early recognition and comprehensive care improve long-term health, well-being, quality of life, and decrease the use of emergency services and hospitalizations. Current evidence-based care guidelines are not easily interpreted in busy care settings.

Methods and Intervention: Using the Institute for Health Improvement (IHI) framework, a periodicity schedule was developed and implemented in a Spina Bifida Clinic Care Partner EMR system. Chart audits were performed to measure utilization and provider interviews were conducted to monitor barriers and adjust for improvement.

Results: In the first month of use, 21 patients with age ranges 0-21 years were seen by 2 providers and charts audits revealed 25% utilization of the periodicity schedule. Follow up with providers assessed barriers and completed the 1st PDSA cycle. A subsequent chart review of an additional 20 patients demonstrated approximately 75% utilization by one provider and 0% utilization by the other. Provider feedback suggested the schedule would be most beneficial to those providers who are not familiar with Spina Bifida care.

Conclusions: The implementation of the intervention is dependent on provider buy-in and perceived benefit. Additional PDSA cycles are needed for continued modification of the schedule to support consistency and documentation of evidence-based guidelines in the care of patients with spina bifida. The periodicity schedule can be used in any care setting, takes minimal additional charting time, and would be helpful for tracking care metrics.

Keywords: Spina Bifida, periodicity schedule, guidelines, comprehensive care, evidence-based care, quality improvement

Demystifying Spina Bifida Guidelines Using a Periodicity Schedule

Problem Description

Approximately 1500 babies are born with spina bifida (SB) each year in the United States (Mai et al., 2019). The severity can vary from mild to severe and could result in minor to severe disability. Recently the Spina Bifida Association (SBA), in conjunction with the Center for Disease Control and Prevention (CDC), released new evidence-based clinical guidelines for the treatment and management of patients with SB to ensure that all people with SB “receive the best and most up to date care possible” (Spina Bifida Association [SBA], 2018, p. 3). Promoting health in a comprehensive manner can reduce gaps in care which improves long-term health and well-being, improves quality of life and decreases utilization of emergency services and hospitalizations over a lifespan (Dicianno et al., 2008 & Webb, 2010). Conversely, a lack of comprehensive care and subsequent gaps in care may contribute to potentially preventable secondary conditions (Fremion et al., 2020). One way this care is achieved is through clinic care partners across the country that provide multi-disciplinary care coordination. Given this concept of using a medical home model, a child’s outcomes can be optimized with improved quality of care in a cost-effective, family centered and coordinated system (Burke & Liptak, 2011). The SBA awards care centers a designation of Spina Bifida Association Clinic Care Partner (SBACCP) and requires exemplary service following evidence-based guidelines. The guidelines are extensive and come in the form of a 247-page document that is cumbersome and difficult to navigate quickly to translate into clinical practice. Development of a toolkit, similar to Bright Futures, would make the guidelines simpler to use and ensure all patients receive appropriate and timely care.

Available Knowledge

Guidelines for the management and treatment of SB were previously available as individual documents. The SBA took three years of planning, extensive literature reviews and utilization of almost 100 volunteers to create the fourth edition of the newly named *Guidelines for the Care of People with Spina Bifida* (SBA, 2018). The *Guidelines* cover topics including the system of care, the psychosocial context of self-management, neuropsychology and neurosurgery, mobility, orthopedics and physical therapy, urology and sexual health, a myriad of special health issues as well as information on early intervention services, individualized educational plans and 504 plans (SBA, 2018). Over 803 manuscripts and 13 websites are cited in the creation of the *Guidelines* (Dicianno et al., 2020). The synthesis of evidence in the *Guidelines* is beneficial to providers but is not practical for implementation.

A toolkit allows a practitioner to apply expected practices (EP). Soni et al. (2016) posits that preliminary data suggests that Eps, which “provide succinct, consistent, and targeted decision support to primary care practitioners and specialists and are built into the daily clinical workflow” help reduce clinical practice variation in large and complex systems. The SBA and CDC workforce compiled the EPs for treatment and management of SB. The issue now is translating the *Guidelines* into a toolkit. A well-known and currently used toolkit is the Bright Futures Handbook. The book is weighty but thorough, much like the *Guidelines*. To simplify use, the Bright Futures Pocket Guide is a smaller, easier to use quick reference. To streamline even further, the American Academy of Pediatrics (AAP) and Bright Futures formulated the periodicity table which takes the recommended screenings and tests for each age and places them into a one-page document (American Academy of Pediatrics [(AAP)] & Bright Futures, 2021).

By utilizing the recommendations put forth by Hempel et al. (2019) for the development of quality improvement toolkits, a toolkit, similar to Bright Futures, will be developed for the *Guidelines*. The content has been determined by the SBA and CDC. Hempel et al. (2019) recommends subjecting the toolkit to usability testing through feedback from end users, observing how users utilize the toolkit, understanding the tools and suggests exploring the specific needs of potential users. The purpose of this project is to develop a toolkit, consisting of a periodicity schedule and chart note template, with stakeholder input, to simplify the implementation of the *Guidelines* in a SBACCP site.

Rationale

The intervention of a periodicity schedule is based on the success, implementation and utilization of the Bright Futures/AAP periodicity schedule for the recommended screenings and assessments at each well child exam, birth through adolescence (AAP & Bright Futures, 2021). Another example of a periodicity schedule specific to specialty care is the Down Syndrome Health Care Guidelines (1999 revision) Record Sheet and subsequent revision (Bull, 2011; Cohen, 1999) and the Marfan Anticipatory Guidance Table (Tinkle & Saal, 2013). The development of electronic health record (EHR) chart note templates will provide a quick way to ensure relevant topics are discussed and documented consistently during routine visits and will decrease variability in care plans and help meet the requirements of the SBACCP designation to provide exemplary evidence-based care. Several studies in other specialty areas have utilized chart note templates to standardize care and improve outcomes (Bensinger et al., 2019; Esper & Walker, 2015; Radhakrishnan et al., 2016; Santoro et al., 2018).

The Spina Bifida clinic is located in a large metropolitan city in the Pacific Northwest and was recently designated as a SBACCP. This multi-disciplinary clinic utilizes a stacked schedule where a patient will see multiple providers on a single day. Socioeconomic status and attributes are linked to outcomes in SB treatment (Schechter et al., 2015), therefore utilizing and completing a uniform chart entry for every patient is one step to ensure appropriate, timely, and equitable healthcare for all individuals with SB. Consistent documentation provides quick access to information such as screenings, education, and guidance given to the patient by any provider as well as making it simpler to determine any potential gaps in care. Radhakrishnan et al. (2016) found that utilization of an electronic charting template to integrate clinical decision supports increased the quality of charting without significantly changing total charting time. Esper & Walker (2015), in their own quality improvement report, found that “SmartPhrases” improved adherence to oncology quality measures. Similarly, Santoro et al. (2018), found that EHR integration of guideline recommendations for Down Syndrome improved adherence. For Bensinger et al. (2019), initiation of a note template showed not only an immediate increase in documentation rates but also prolonged and sustained documentation rates. Given these multiple studies showing efficacy of utilizing EHR systems to adhere to guidelines, specifically in specialty areas, the development of a similar toolkit for SB should increase adherence to the *Guidelines*. If national guidelines are simplified into a toolkit, then visits will be standardized and structured. This provides all patients consistent and predictable care with all needs addressed systematically and completely so that the highest care is achieved. Utilizing a PDSA cycle will allow for initial development and evaluation of a periodicity schedule and subsequent chart note templates and determine the usability of these tools to fit the needs of this specific clinic.

Multiple PDSA cycles will be required to fully implement appropriate and usable chart note templates.

Specific Aims

The aim of this study was by December 2021, providers would use the periodicity schedule in a standardized format in 75% of patients seen in the SB clinic. All providers will report knowledge and confidence in using the toolkit.

Methods

Context

The SB clinic operates within an academic teaching hospital. The multi-disciplinary center serves patients and families, offering a “one-stop-shop”: where a patient will see multiple providers on the same day. Families are seen prenatally if diagnosis is known prior to birth and then patients are seen every 3 months until age one, every 6 months from the age of one until age 6 and then annually and as needed until age twenty-one. Currently about 470 individuals are receiving on-going care. Transition services to adult providers are still being developed and are part of an on-going improvement project not included in this project.

The SB team is comprised of a developmental pediatrician/child neurologist, pediatric nurse practitioners, physical and occupational therapists, pediatric urologists as well as special education, psychology, audiology, speech therapy, and orthopedics. There are two pediatric nurse practitioners that serve as the hub of the team, creating a cohesive note with the whole team’s plan at the end of the visit day. This document serves as a reference to families regarding the care plan. The toolkit should decrease variability in care by ensuring all relevant screenings and tests are done for each age demographic. The toolkit may also help other members of the interdisciplinary team find relevant information faster by standardizing documentation. During

the provider visit there are five key areas for discussion and assessment which constitute the “Big 5” of SB care (SBA, 2018). These include 1) lesion level and function, including equipment and therapy needs, 2) neurosurgical care including imaging needs and shunts, 3) bladder care, 4) bowel care, and 5) skin.

Anticipated barriers to success on this project are time constraints of the provider visit and potential integration issues with the EHR system as well as the length of the project. In discussions with the providers, the plan of utilizing the periodicity schedule and chart note template will increase the ability to address key topics in SB care. The schedule will also help track discussions to ensure topics are covered over time. It can be difficult to integrate new templates into the EHR system; therefore, the effectiveness of the created templates will need to be assessed. The project lead is also new to implementing “SmartPhrases” into an EHR system and this could be a barrier to project implementation and data collection. The project length will allow for a short longitudinal study to assess if utilization of the periodicity schedule increased discussed and documented topics over time. The effect of the COVID-19 pandemic will need to be taken into consideration as this may impact the number and type of appointments in a given time period. Anticipated facilitators to this project include provider involvement and desire for the creation of this toolkit. Contextual factors that cannot be controlled include the finite amount of time for each appointment, “can of worms” scenarios of one topic taking an entire visit to discuss, emergency situations that may override a general appointment format, “did not keep” appointment rates, and finally the inability to force providers to use the toolkit. This final contextual factor was balanced by the desire of the providers to have this toolkit created and therefore having a vested interest in its utilization.

Interventions

The proposed quality improvement project began with the development of a periodicity schedule, similar to the Bright Futures/AAP periodicity schedule, Down Syndrome Health Care Guidelines record sheet and Marfan Anticipatory Guidance Table, discussed previously. This schedule was developed with stakeholder input and will serve to simplify the *Guidelines*. The schedule was then used to create a chart note template “SmartPhrase” to provide a standardized method of documenting the covered information.

The initial PDSA cycle involved developing the periodicity schedule and collecting feedback from the providers to determine usability. The schedule was then translated into a “SmartPhrase” that will also be implemented in the SB clinic. Provider utilization was assessed through the addition of questions at the end of the “SmartPhrase” that asked 1) was the periodicity schedule used Y/N and 2) utilization of the periodicity schedule and “SmartPhrase” increased charting time: 0) not at all, 1) 1-2 minutes, 2) 3-5 minutes or 3) > 5 minutes. This data was collected from all kept appointments after each month of use with a projected 40 charts based on conversations with the providers in clinic. We planned to survey providers on their knowledge and confidence in using the *Guidelines* through a pre/post survey on implementing the toolkit at baseline and 1, 2, and 3-months post-implementation. The implementation of any future templates and the number of PDSA cycles will be dependent on the results of the provider surveys, chart audits, revisions needed and time required for completion of this first cycle.

Study of the Interventions

To establish a baseline of current *Guideline* utilization, providers were surveyed regarding the ease of use of the current format and satisfaction with current charting methods. We will know the toolkit was effective in increasing discussion and documentation of the

Guidelines by consistent utilization and completion of the “SmartPhrase” template. We used surveys to assess confidence and knowledge of the toolkit and to further understand the impact on providers with higher scores on the pre/post survey indicating a positive outcome. Field notes were collected throughout the project with each PDSA cycle, monitored for barriers and facilitators, and informed future changes. Virtual visits were not utilized in this SBACCP. All completed visits in-person visits, were assessed for utilization of the toolkit.

Measures

The overall goal of this project was to standardize screening and charting of SB patients. The outcome measure was that the toolkit would be utilized and documented in at least 75% of patients in the SB clinic. A chart audit was completed at the end of each month of all completed office visits with an anticipated 40 charts given current visit census. A run chart was utilized to visualize the number and percentage of patients with documented use of the toolkit compared to the total number of charts completed. The process measure was the impact on charting time which was assessed by monitoring the answer to the charting time question imbedded in the “SmartPhrase.” Provider interviews were completed after the implementation of the periodicity schedule and “SmartPhrase” as well as after any refinements.

Analysis

The project was analyzed quantitatively based on the percentage and number of charts that had documented utilization of the periodicity schedule and “SmartPhrase” and an increase in percentage would have indicated success of the intervention. Provider feedback was collated to report on knowledge and confidence and a higher number would have indicated more knowledge and confidence. As there are only two nurse practitioners in this SB clinic, variation should be easily recognizable and minimal in the implementation and utilization of the toolkit. The second

process measure was the charting time and impact of utilizing the toolkit. Data was collected using the embedded question in the SmartPhrase and a bar graph was utilized to determine the percentage of encounters that resulted in increased time spent charting. If the templates increased charting time and delayed the schedule then this intervention is not effective and refinements will be needed. The provider survey included a question regarding the impact of the toolkit on charting time and their interpretation of the impact on patient care.

Ethical Considerations

Chart audits only looked for utilization of the periodicity schedule and “SmartPhrase” and did not collect any personal health information (PHI). One concern was that the chart review may reveal certain guidelines that are not addressed consistently, however given the aim of this project is to ultimately standardize care and improve outcomes, recognition of any gaps is paramount for improvement. This proposal was evaluated by the site-specific Investigational Review Board (IRB) and was deemed ‘not human research’. The principal investigator has no conflicts of interest or financial disclosures.

Results

The initial proposed intervention included using provider feedback to develop a periodicity schedule (Appendix). Other modifications to the interventions included adding the schedule to the tracking “SmartPhrase” to streamline use, and allowing for future tracking of SBACCP metrics for quality improvement. Providers requested specific measures be added to the schedule to address “hard to remember and newer” areas of the *Guidelines* including sexuality, growth hormone or endocrine issues and mental health. The development of this periodicity schedule and “SmartPhrase” required several edits and more time than anticipated which reduced the available time for implementation and limited a complete study of the

intervention. After implementation providers found the schedule to be comprehensive but felt that it would be most useful for primary care providers or those new to a specialty care center. The outcome measure of utilization in patient charts only reached 25% rather than the planned 75% after 5 weeks with the assessment of 21 provider encounters. The process measure which assessed for impacts on charting time, showed no increase in documentation time with the utilization of the periodicity schedule initially. A meeting was held with the providers to discuss initial results, address barriers and contextual elements contributing to the utilization of the schedule and “SmartPhrase,” and concluded the first PDSA cycle. Providers reported knowledge in using the periodicity schedule but one provider felt the schedule would not be useful in their own workflow. A subsequent chart review of 20 charts after 4 weeks showed approximately 75% utilization by one provider and 0% utilization by the other provider. Those encounters that used the periodicity schedule did report an increase in charting time ranging from 1-5 minutes however the provider did not feel the increase was unsustainable or detrimental to workflow. Contextual elements affecting the outcome measure included perceived benefit, miscommunication about the expected intervention, and the initiation of another quality improvement project in the clinic.

Discussion

Summary

This quality improvement project was undertaken in collaboration with providers to fill a gap in SB care by developing a periodicity schedule. The goal of simplifying the *Guidelines* by standardizing and structuring the care visit without negatively impacting charting time was achieved, but required multiple iterations to accomplish a useable schedule. Literature supports the development of periodicity schedules and chart note templates to standardize care and

improve outcomes (Bensing et al., 2019; Bull, 2011; Cohen, 1999; Esper & Walker, 2015; Radhakrishnan et al., 2016; Santoro et al., 2018). Key findings of this project include; the development of a tool for clinical practice requires multiple iterations and time, collaboration with key stakeholders is essential for implementable change, and provider buy-in does not guarantee positive results. Low perceived usefulness and misunderstanding of the premise of this project contributed to the lack of utilization by one provider and affected the overall results of the project. A strong outcome from this work is the development of a periodicity schedule that takes minimal additional time for charting and could be utilized in any care setting for individuals with SB.

Interpretation

When developing a toolkit, Hempel et al. (2019) recommends searching for existing tools, involving experts and pilot testing in practice for usability. These recommendations and suggestions were taken into consideration while creating this periodicity schedule and “SmartPhrase.”

Existing schedules (AAP & Bright Futures, 2021; Bull, 2011; Cohen, 1999; Tinkle & Saal, 2013) supported the development of this schedule as a useful tool. These schedules are used in primary care and specialty care clinics and the format is recognizable to many practitioners. The structure of the SB periodicity schedule mirrored these known tools.

The experts that developed the *Guidelines* took many years to synthesize the data (Dicianno et al., 2020) and the full report was utilized to develop this periodicity schedule. The *Guidelines* are comprehensive and this schedule only serves as an adjunct to provide a quick reference for those caring for individuals with SB and to prompt further inquiry. The periodicity

schedule was created based on provider input requesting an intervention that would signal areas of assessment and discussion at each appointment age.

Initial support of the project was robust however the proposed intervention and recommendations did not meet provider expectations and negatively impacted the overall results of the project. Our outcome did not mirror Santoro et al. (2016) who found stakeholder buy-in and education improves adherence to guidelines for Down Syndrome. While the schedule simplifies the *Guidelines* from 247-pages to a one-page document it did not meet provider expectations. Similarly, the integration of guideline recommendations into an EHR system was helpful (Santoro et al., 2018) but one provider reported that the increase in charting time of even a few seconds to use the schedule would be too much to sustain in their own practice. This project sought to incorporate provider requests and recommendations into the intervention but failed to meet the expectations of one provider. The integration of the schedule into the EHR “SmartPhrase” increased utilization by one provider and will simplify monitoring of future quality metrics if it is used.

Given the short implementation window and low utilization during the first two PDSA cycles, long-term utilization or sustained results were unable to be obtained. A study conducted longitudinally supports the assertion that continued improvements with provider feedback is needed to determine if the periodicity schedule is useful for increasing adherence to the *Guidelines* and meeting quality improvement metrics required for a SBACCP (Bensinger et al., 2019).

Consistent documentation would provide quick access to information such as screenings, education, and guidance given to the patient by any provider as well as making it simpler to determine any potential gaps in care. The periodicity schedule was only utilized by one provider

however chart audits revealed very different charting styles by each provider that would make monitoring for any gaps difficult without the use of a standardized tool. This schedule, although not used consistently, met the goal of the providers in the clinic to develop a method of effectively tracking SBACCP metrics.

Limitations

The limitations of this project included an abbreviated implementation window and a small number of providers in an established SBACCP with which contributed to intermittent utilization. Conversations with providers at the end of the first PDSA cycle revealed that a second quality improvement project was being piloted in the SBACCP which may have impacted the utilization of this toolkit as time and energy is split between two separate projects.

Conclusion

The toolkit, if utilized and documented consistently, would be helpful in tracking specific quality improvement measures and ensure metrics are met to maintain SBACCP status. In another setting, such as a primary care clinic or with a new practitioner, the toolkit could be used to ensure that relevant and important topics are discussed at appropriate visits. After implementation in this SBACCP, one provider chose to continue using the periodicity schedule while the other does not plan to adopt the use of this toolkit. Future PDSAs could assess implementation or determine other interventions that may be more useful for all providers.

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Appendix

Spina Bifida Periodicity Schedule

	Prenatal	Birth	3 mo	6 mo	9 mo	12 mo	18 mo	2 yr	2.5 yr	3 yr	3.5 yr	4 yr	5 yr	6-13 yr	14-21 yr
Maternal-fetal medicine															
Spina Bifida clinic consult/visit															
Lesion level and function															
Neurosurgical care	In utero surgical repair ?	Primary lesion repair												Yearly	Yearly
Neuroimaging	Ultrasound or MRI														
Shunt care															
Chiari Malformation															
Tethered Spinal Cord															
Bladder care															
Urology Consult															
CIC ¹ teaching	Parent (P)	P	P	P	P	P	P	P	P	Self (S)	S	S	S	S	S
Renal ultrasound		By 3mo ²												Yearly	Yearly
Urodynamic studies		By 3mo ³													
Serum Creatinine		By 3mo ⁴												Yearly	Yearly
Bowel care															
Neurogenic bowel															
Constipation care															
Sitting schedule															
Skin															
Assess/Breakdown															
Latex allergy															
Orthopedic eval/surgery															
Equipment and therapies															
School, learning, work															
Sexuality															
Mental Health															
Parents, patient, family															
Anticipatory guidance															
Resources: SBA ⁵ and CDC ⁶															
Reproductive health ⁷															
Genetic Counseling															

Gray shaded boxes to be completed as needed

¹ CIC – clean intermittent catheterization

² By 3 months and then every 6 months until 6 years and prn

³ By 3 months and then yearly at ages 1, 2 and 3 years and prn

⁴ By 3 months and then yearly starting at age 5 years

⁵ Spina Bifida Association

⁶ Center for Disease Control and Prevention

⁷ Prenatal counseling and preventative care including folic acid for all females of child-bearing age