

Enhancing Accessibility of Patients with Cleft Lip/Palate to Healthcare Services via a Cleft Birth Registration System

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Background: Cleft lip/palate is a critical health problem in Thailand; with an incidence rate of 2.49/1,000 live births. To insure the best outcomes, surgery should be performed near the age of three months. However, during the years 1993-2007, only 39.7% of children with a cleft lip/palate underwent an operation by the age of 3-4 months and only 58.18% by the age of 9-12 months.

Objective: The purpose of the study is to determine if a cleft birth registry might facilitate timely and proper treatment for children with a cleft lip/palate.

Material and Method: A pilot cleft birth registry, developed by the Tawanchai Cleft Center, was made available to hospitals in Khon Kaen, Roi-et, Kalasin, and Mahasarakham provinces, Thailand. Ninety-eight personnel involved in the care of children with a cleft lip/palate were recruited from the participating hospitals to evaluate the system. Assigned to one of four focus groups, participants were asked to evaluate the pilot system in terms of satisfaction and benefit. Following the focus groups, those participants that were traditionally responsible for registration were asked to use the cleft birth registry to register any newborns with a cleft lip/palate that were encountered in the course of their duties. Records were examined to determine how many newborns were properly registered and for those registered, whether proper care was received in a timely manner.

Results: With 78 focus group participants responding to the satisfaction survey, results indicated mostly high levels of satisfaction with 26 (33%) participants rating satisfaction as very good, 49 (63%) as good and 3 (4%) as fair. No participant rated satisfaction below fair. Furthermore, a majority stated that the cleft birth registry would benefit patients and contribute to timely treatment.

During two years of active use, one hundred and thirty-seven newborns with a cleft lip/palate were registered into this cleft birth registry. Subsequent examination showed that eighty-eight percent of registered cases received proper management in tertiary healthcare settings.

Conclusion: The fact that most of registered cases received proper care suggests that a cleft birth registry has the potential to facilitate timely and proper care. However, declining rates of registration over time is cause for concern. One opportunity for improvement in this regard might come from the establishment of an in-service training program to update knowledge pertaining to current standards of care and effective case management. Further improvements could also be made through better integration with existing referral systems.

The researchers also noted that the existing electronic patient records (EPRs) in use by participating hospitals often lacked data structures suitable for effective care of patients with a cleft lip/palate. Thus, to foster useful integration, existing EPRs must also be extended to include data specific to cleft care/management.

Keywords: Cleft lip/palate, Birth registration system, Healthcare service accessibility

J Med Assoc Thai 2014; 97 (Suppl. 10): S32-S36

Full text. e-Journal: <http://www.jmatonline.com>

In general, Cleft lip/palate refers to the condition in which both the palate and lip are cleft. Worldwide, about one in 1,000 babies are born with

cleft lip/palate⁽¹⁾. However, in Thailand, Cleft lip/palate represents a more pervasive health problem, with an incidence rate of 2.49 per 1,000 live births⁽²⁾.

Ideally, cleft care should be given from birth; helping the child to breast feed until his/her body weight is high enough to sustain the burden of surgery. To insure the best outcomes, surgery should usually be performed between the ages of 10 to 12 weeks. However,

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during the years 1993-2007, only 39.7% of children with a cleft lip/palate in Thailand underwent an operation by the age of 3-4 months and only 58.18% by the age of 9-12 months.

Beyond this initial surgery, follow-up care should be provided through to age 16. However, to satisfy the additional needs of these patients fully over this span post surgery, a multidisciplinary approach is needed. Given recent trends, it was thought that an electronic means of coordination would possibly lead to improvements in clinical outcomes such as quality of care, patient safety, and patient outcome measures, as well as reduce treatment errors. Organizational outcomes might see improvement in patient and healthcare provider satisfaction and efficient financial and operational performance. Furthermore, improved data collection might benefit society through research and support of evidence-based care. Much of the current literature reflects data obtained from academic institutions and large health maintenance organizations where integrated EHRs were first implemented. More community oncology practices have adopted EHRs and are noting similar outcomes⁽³⁾.

With increasing adoption of EHRs, a cleft lip/palate specific birth registry might serve to provide a reliable means to get information regarding the nature of the patient's cleft lip/palate into the health records. Once embedded, it is hoped that this information will facilitate coordination of the lengthy follow-up care. To assess all of these aspects of the issue, this study was divided into two phases:

Phase 1: Assess the usability of a prototype cleft birth registry.

Phase 2: Assess how effectively a cleft birth registry might facilitate timely and proper treatment for patients with cleft/palate.

Objective

The purpose of the study was to determine if a cleft birth registry might facilitate timely and proper treatment for children with a cleft lip/palate.

Material and Method

Phase 1: Assessing usability

While making initial plans for the development of a cleft birth registry, the researchers noted that the existing electronic patient records (EPRs) in use by participating hospitals often lacked data structures suitable for effective care of patients with a cleft lip/palate. Because of this, it was decided to construct a stand-alone registry to allow use by many different

institutions without the need for the time-consuming work that would be required to design integration solutions for each.

After the prototype cleft birth registry was developed, the Tawanchai Foundation tested its usability through workshops. As it was desired to assess usability with regard to the likely users, invitation letters were sent to both public and private hospitals, inviting them to send one or two personnel who regularly participate in cleft care. Letters were sent to institutions in four provinces as follows:

- 28 hospitals in Khon Kaen
- 20 hospitals in Roi-et
- 16 hospitals in Kalasin
- 12 hospitals in Mahasarakam

Ninety-eight healthcare providers agreed to attend the workshop, with the full contingent consisting of 1 physician, 12 dentists, 73 nurses and 12 allied health practitioners from provinces as follows:

- 41 healthcare providers from 15 hospitals in Khon Kaen
- 26 healthcare providers from 15 hospitals in Roi-et
- 18 healthcare providers from 10 hospitals in Kalasin
- 13 healthcare providers from 8 hospitals in Mahasarakam

The workshop took place in March, 2012. Participants were assigned to one of four focus groups, with each group representing one province. The procedures for all four focus groups were structured so as to minimize differences between them. In all cases, the participants were asked to review the prototype stand alone birth registry described above. While reviewing the prototype of the cleft birth registry and engaging in interactions with a live instance, workshop participants were asked to brainstorm three questions: 1) What are the expected benefits from birth registry (for patients, for healthcare providers, for the cleft health care system and for their own organization)? 2) Who would be the right person to register? 3) What do they need (in terms of incentives and assistance) to register data? At the conclusion of the workshop, the participants were then asked to complete a satisfaction survey regarding the prototype cleft birth registry.

Phase 2: Assessing effectiveness

At the conclusion of the workshop, follow-up letters were sent to all focus group participants. The letter requested that those who were charged with birth registration at their respective institutions actually

use the stand-alone prototype cleft birth registry for three months to register any newborns with a cleft lip/palate who were encountered in the course of their duties. All participants agreed to use the system actively for a 2-year window, during which active use was monitored. This active use occurred in staggered episodes between April 2012, and March 2014. At the conclusion of the 3-month active use period for each participant, records were examined to determine how many newborns were properly registered and, for those registered, whether proper care was received in a timely manner.

After participants concluded their active use of the prototype system, the researchers sent a follow-up letter asking for feedback regarding things that could be improved. The responses were pooled, reviewed and common themes derived.

Results

Phase 1: Assessing usability

After participants were allowed to interact with the prototype cleft birth registry, they were asked to brainstorm responses to three questions in reaction to the prototype cleft birth registry. Samples that represent the most cogent responses to arise from this process are as follows:

Question 1: "What are the benefits of birth registry?"

Benefits to patients:

- Patients would receive continuing care, faster responses, and broader coverage.
- Patients would be better able to enforce their rights to care.

- Patients would have a better quality of life.

Benefits to their own organization:

- Ability to know what care patients received and ease follow-up.

- Adding comprehensive cleft data to existing databases.

Benefits to the cleft care system:

- Provides for continuity of patient data.

- Allows for better networking.

- Facilitates timely follow-up of care.

Benefits to healthcare providers:

- Provides personal fulfillment knowing that they can provide better help.

- Allows providers to coordinate with others and strengthen networking.

- Better enables nurses to carry out their role.

Question 2: "Who would be the right person to register?"

Healthcare providers from, hospitals where babies were born, the labor room

Question 3: "What do they need (in terms of incentives and assistance) to register data?"

- Convene a meeting twice a year to follow-up and receive updated information regarding the patients with cleft in their area.

- Organize a conference related to disease management, case management.

- Develop clinical practice guidelines for a referral system.

- Establish a strong regulatory policy regarding cleft birth registry.

A majority of participants also felt that a cleft birth registry would benefit patients and contribute to timely treatment.

At the conclusion of the workshop, participants were asked to complete a satisfaction survey. With 78 focus group participants responding to the satisfaction survey, results indicated mostly high levels of satisfaction, with 26 (33%) participants rating satisfaction as very good, 49 (63%) as good and 3 (4%) as fair. No participant rated satisfaction below fair.

Phase 2: Assessing effectiveness

After the conclusion of the focus groups, from April 1 through March 31, 2014, the prototype was put into active use throughout the four provinces. The prototype cleft birth registry used in a live setting by all participants. During this period of active use, one-hundred and thirty-seven newborns with a cleft lip/palate were registered into this cleft birth registry. Subsequent examination showed that eighty-eight percent of registered cases received proper management in tertiary healthcare settings.

137 cases registered: male 82 (59.8%), female 55 cases (40.2%)

- 68.61% (94 cases) received treatment at Srinagarind hospital

- 10.95% (15 cases) received treatment at Khon Kaen hospital

- 8.76% (12 cases) received treatment at other hospitals

- 8.03% (11 cases) lost data

- 3.65% (5 cases) died due to other congenital defects such as heart disease, gastroschisis.

Discussion

The workshops dealt exclusively with a completed prototype. Thus, the workshop participants were not directly involved in the development of the

prototype cleft birth registry. Rather, they were asked to provide feedback on a functional prototype prior to using the prototype in a live environment. Having nurses with field experience involved in the development phase could have improved the system.

During the development of the prototype, the researchers noted that the existing electronic patient records (EPRs) in use by participating hospitals often lacked data structures suitable for effective care of patients with a cleft lip/palate. Thus, to foster useful integration, existing EPRs must also be extended to include data specific to cleft care/management.

The World Health Assembly resolution states that one of the strategies to promote primary prevention and the health of children with congenital anomalies is to develop and strengthen registration and surveillance systems⁽⁴⁾. The system developed for the purposes of this study has the potential to enhance both. The Cleft Birth Registration System implemented in this study did demonstrate an increase in access of patients with cleft lip/palate to care. However, further work must be done to characterize fully the active use of the prototype to see if improvements can be made to strengthen the benefits of registration. At a minimum, other databases must be manually crosschecked to determine how many children with cleft lip/palate might have been missed at institutions where the prototype was in active use.

The data show that 137 cases of cleft lip/palate have been registered with the system, with approximately 87 percent of those received care at the appropriate time. However, declining rates of registration over time is cause for concern. One opportunity for improvement in this regard might come from the establishment of an in-service training program to update knowledge pertaining to current standards of care and effective case management. The registry used in this research represented a stand-alone system that required extra attention from staff in order to use it. Thus, further improvements might be gained through better integration with existing referral systems. This might represent the largest challenge to full implementation as fostering useful integration will require that existing EPRs be extended to include data specific to cleft care/management. However, the likely benefits make this an endeavor worth pursuing.

Conclusion

The development of a cleft birth registry

system capable of good integration with existing EHRs represents a tall challenge. However, the development of a stand-alone prototype does show that the potential benefits make this a worthwhile effort. A large percentage of workshop participants indicated that they were satisfied with the usability of the prototype. The workshops identified multiple key benefits that might follow implementation of such a system. These results were encouraging enough to pursue the second phase of this study to explore how effective implementation of such a registry in a live environment might be. The fact that 87% registered cases received proper care suggests that a cleft birth registry has the potential to facilitate timely and proper care. Given the historically poor record in Thailand, this result provides strong evidence that a cleft birth registry can be an effective tool in improving cleft care.

Acknowledgement

The authors wish to thank (a) the Center for Cleft Lip-Cleft Palate and Craniofacial Deformities, Khon Kaen University in association with Tawanchai Project for financial support (b) the healthcare providers from 4 provinces for Cleft Birth Registration.

Potential conflicts of interest

None.

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การศึกษาการเข้าถึงบริการสุขภาพของผู้ที่มีภาวะปากแห้ง/เพดานโหว่ผ่านทางระบบทะเบียนแรกเกิด

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ภูมิหลัง: ภาวะปากแห้ง/เพดานโหว่เป็นปัญหาสาธารณสุขที่สำคัญของประเทศไทยโดยมีอุบัติการณ์ของภาวะนี้ 2.49 รายต่อเด็กแรกเกิด 1,000 ราย ซึ่งผู้ป่วยเหล่านี้ควรได้รับการผ่าตัดเมื่ออายุ 3 เดือน แต่พบว่ามีเพียงร้อยละ 39.7 ของเด็กที่มีภาวะนี้ได้รับการผ่าตัดในเวลาดังกล่าว

วัตถุประสงค์: เพื่อประเมินผลการพัฒนาระบบการลงทะเบียนแรกคลอดสำหรับเด็กที่มีภาวะปากแห้ง/เพดานโหว่ ทางด้านการได้รับการดูแลรักษาตามระยะเวลาที่เหมาะสม

วัสดุและวิธีการ: มุลินธิคะวันฉายเพื่อผู้ป่วยปากแห้ง/เพดานโหว่และพิการทางศีรษะและใบหน้า ได้พัฒนาระบบลงทะเบียนทารกแรกเกิดที่มีภาวะปากแห้ง/เพดานโหว่ ได้มีการศึกษานำร่องในจังหวัดขอนแก่น ร้อยเอ็ด กาฬสินธุ์และมหาสารคาม ทั้งนี้มีบุคลากรที่เกี่ยวข้องกับการดูแลผู้ป่วยที่มีภาวะปากแห้ง/เพดานโหว่จำนวน 98 รายเข้าร่วมประเมินระบบดังกล่าวโดยวิธีการจัดกลุ่มสนทนา หลังจากนั้นมีการประเมินผลการใช้ระบบถึงการติดตามการรักษาดูแลผู้ป่วย

ผลการศึกษา: ผลการประเมินโดยการจัดกลุ่มเสวนาพบว่าผู้เข้าร่วมประเมินระบบจำนวน 78 ราย ทั้งนี้ผู้ใช้ส่วนใหญ่มีความพึงพอใจต่อการใช้ระบบลงทะเบียนทารกแรกเกิดที่มีภาวะปากแห้ง/เพดานโหว่ อยู่ในระดับพึงพอใจสูงมากจำนวน 26 ราย (ร้อยละ 33) พึงพอใจมากจำนวน 49 ราย (ร้อยละ 63) และพึงพอใจปานกลางจำนวน 3 ราย (ร้อยละ 4) นอกจากนี้ยังระบุว่าระบบดังกล่าวจะเป็นประโยชน์กับผู้ป่วยและเฝ้าต่อการได้รับการรักษาที่เหมาะสมต่อไป

ผลจากการทดลองใช้ระบบฯ 2 ปี พบว่ามีผู้ป่วยที่มีภาวะปากแห้ง/เพดานโหว่ลงทะเบียนในระบบจำนวน 137 รายพบว่าผู้ป่วยร้อยละ 88 ได้รับการดูแลรักษาต่อที่โรงพยาบาลตติยภูมิอย่างเหมาะสมและทันเวลา

สรุป: จากผลการศึกษาพบว่าผู้ป่วยที่มีภาวะปากแห้ง/เพดานโหว่ที่ลงทะเบียนในระบบส่วนมากได้รับการรักษาที่เหมาะสมและทันเวลา แต่อย่างไรก็ตามการลงทะเบียนมีแนวโน้มที่จะลดลงบ้าง ดังนั้นจึงควรมีการติดตามการใช้งานและการให้ความรู้เกี่ยวกับมาตรฐานการดูแลผู้ป่วยที่มีภาวะปากแห้ง/เพดานโหว่เพื่อกระตุ้นให้ผู้ใช้ระบบฯเห็นความสำคัญและใช้งานระบบอย่างต่อเนื่องและถ้าระบบฯนี้สามารถเชื่อมโยงกับระบบเวชระเบียนผู้ป่วยจะทำให้การดูแลผู้ป่วยที่มีภาวะปากแห้ง/เพดานโหว่นี้เป็นไปได้ด้วยมีคุณภาพยิ่งขึ้น
