GunderKids: Design of a Clinical Care Management Program for Parents With Substance Abuse and Their Newborn Children with a Focus on Preventing Child Abuse

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ABSTRACT

Background: In response to an increased need to care for babies born to mothers with substance abuse issues, we developed GunderKids, a care management program that provides integrated medical care beyond standard-of-care, well-child appointments for these socially complex families.

Methods: The program incorporates frequent visits to the pediatrician and the care team, which includes pediatric nurses, a pediatric social worker, and a child psychologist. Enrollment is voluntary. Each visit addresses parenting challenges, home environment, basic needs, safety issues, and maintenance of sobriety, as well as child development and health issues.

Results/Discussion: We found that mothers and fathers (or parents) welcome intense support following delivery, appreciate the relationship that is built with the care team, and prefer frequent visits at the medical center over in-home visits, which they perceive as potentially intrusive. We describe here the planning and implementation of the program, as well as insights gained in our first year.

BACKGROUND

Illicit drug use by the mother during and after pregnancy may have severe consequences for the newborn child. Children born to these mothers may sustain not only immediate effects from their mothers' substance abuse, such as low birth weight, neonatal abstinence syndrome (NAS), and complications attending preterm birth, but also long-term effects, such as difficulties with learning and behavior.[1] During childhood, they are more likely than their unaffected counterparts to experience or witness emotional, physical, or sexual abuse[2]—3 times more likely to be abused and 4 times as likely to be neglected.[3] Furthermore, these experiences are strong predictors of decreased well-being and social functioning, increased health risks, and compromised learning.[4,5] Indeed, these children often develop destructive emotional and social behaviors and, as adults, perpetuate the cycle of abuse they witnessed as children.[6] Finally, according to the US Department of Health and Human Services, parental substance abuse was a factor in 32.2% of cases in which children were placed in foster care in 2015, an increase of 3.7% over 2012.

Parents with substance abuse issues are 4 times less likely than parents without substance abuse issues to seek well-child care for their baby.[7] The mothers' fear of being judged keeps them from seeking regular health care or from accepting community resources.[7] They routinely decline community support services, such as Healthy Families, because they fear their child will be taken away. Thus, programs that build trusting, supportive relationships could encourage these parents to avail themselves of services that support healthy parenting.

To our knowledge, our program is the only clinic-based program focused on preventing child abuse in this population. Treatment and rehabilitation facilities and drug court programs assist these individuals in attaining and maintaining sobriety, but their focus is on abstaining from drug use, not on healthy parenting. There are effective programs with a relationship-based, nonjudgmental approach similar to that of GunderKids, but they are home-based—for example, CEDEN (Center for Development, Education, and Nutrition) and the Prenatal and Early Childhood Nurse Home Visitation Program—and are open to children of all high-risk mothers, not only those whose mothers have substance use disorder.[8]

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Box 1. Metrics Collected by the GunderKids Program

- Baby growth velocity
- Immunization compliance
- Number of GunderKids appointments kept by the family
- Number of emergency department/urgent care visits
- Number of hospital admissions
- Completion of behavioral health visits
- Parenting Stress Index (PSI) score analysis
- Child Abuse Potential Inventory (CAPI) score analysis
- Number of specialty appointments missed
- Percentage of patients improving on caregiver satisfaction and caregiver well-being
- Number of patients with a diagnosis of maltreatment
- Number of parents maintaining custody

Plan Development and Implementation

We developed GunderKids to provide anticipatory guidance, support services, and parenting education for at-risk families to prevent child abuse. A pediatrician and a social worker dedicated to working with this at-risk population envisioned the GunderKids program to prevent parents at high risk from abusing or neglecting their baby. Several steps were taken within Gundersen Health System departments to develop communication and the infrastructure necessary to conduct a pilot of the GunderKids program in this high-risk population. The pediatric department's clinical manager was approached, and her support was obtained for the pilot program. Approval for nursing support also was granted. Specifics of the program were then developed—visit structure, education to be provided at each visit, screening tools, and metrics. A project manager was assigned to assist with operational and program development. Webinars and a literature review provided necessary education about issues that were likely to be encountered in the pilot population.

A high-risk obstetrics team at Gundersen Health System had provided prenatal care for this population for several years. The model of care they used had been well-received, with patients often expressing a desire for it to continue postpartum. This care model involved an obstetrician, 2 nurse care coordinators, and a social worker who met with the expectant mother throughout the pregnancy. Patients were encouraged to receive therapy through Gundersen's addiction medicine department, which worked closely with this obstetrics team. The obstetrics team met with the GunderKids program developers to share their insight and experience. They were enthusiastic about the prospect of this new program and eager to partner with pediatrics to support it.

The GunderKids program was patterned after that of the successful high-risk obstetrics team program, emphasizing relationship building as the model for interaction with the parents. We developed a system of patient referral from the obstetrics team to our GunderKids nurses, who would meet with the expectant parents during a prenatal appointment to introduce the program and invite future participation. The GunderKids program planners also met with the pediatric hospitalist team. The program was discussed with an emphasis on working together to ensure a smooth transition of care once babies were ready to leave the hospital. At Gundersen Health System, most babies with NAS begin their stay after birth on the postpartum unit with their mothers. Babies who require a prolonged hospital stay for treatment of NAS are moved to the inpatient pediatric unit, which is on the same floor as the postpartum unit. The pediatric hospitalists manage the care of the newborn until discharge. Very few babies with NAS go to the neonatal intensive care unit unless they have other health issues, such as prematurity, infection, or a congenital problem requiring immediate intervention. The GunderKids team attended nursing staff meetings for the newborn nursery, the neonatal intensive care unit, and the inpatient pediatrics unit to provide information on the new GunderKids program and to improve coordination of care.

Infrastructure Development

Necessary enhancements to the electronic health record (EHR) were identified. Templates for visit type were developed, and some of the screening tools to be used in the program were incorporated into the EHR (Box 1). There was a need to be notified electronically when mothers delivered and when babies enrolled in GunderKids were seen in other health system departments. The Gundersen quality improvement department assisted in the development of metrics to measure program outcomes; metrics data needed to be part of the EHR, as well. Information systems met with the team several times and incorporated all of these features into the EHR.

The Pilot: Structure and Insights

The GunderKids pilot program launched on December 1, 2015. More babies were quickly enrolled than had been anticipated. Parents were engaged and keeping appointments far better than was expected. Many were wary at the first few visits and expressed worry that GunderKids was aligned with Child Protective Services with the goal of taking their baby away. By the third to fourth visit, a trusting relationship had developed with most families, and parents began expressing the value they felt for the benefits of the program.

Given how rapidly the program was growing, the pediatric clinical manager requested an efficiency/time evaluation for the GunderKids pediatrician and nurses to determine GunderKids' capacity in the current practice structure. A meeting was held with administration to review efficiency results and to request formal support of the program, which was granted.

The obstetrics and GunderKids teams, as well as representatives from the inpatient pediatric, nursery, and pediatric hospitalists group, began meeting monthly, staffing each patient and address-

ing program development issues. Staff meetings were periodically dedicated to ongoing learning. For example, a pediatrics occupational therapist taught the group about the soothing techniques she teaches to parents of babies with NAS while they are still in the hospital. At another, a La Crosse County therapist taught the team about attachment disorder.

The Newborn Behavioral Observations (NBO) system, a program of the Brazelton Institute based at Boston Children's Hospital, provides ways to enhance attachment for newborns and their caregivers. Nurses trained in NBO help parents understand what their baby is trying to communicate and help with bonding. Babies born to mothers with addictions are at high risk for attachment disorder, so NBO would be a beneficial part of the GunderKids program. Gundersen Medical Foundation agreed to fund NBO training for the GunderKids nurses in Boston.

Once the pilot was underway, the GunderKids team met with the nursing research department to discuss possible research studies. The GunderKids research team was formed, and meetings were held biweekly to develop research protocols and identify possible funding sources.

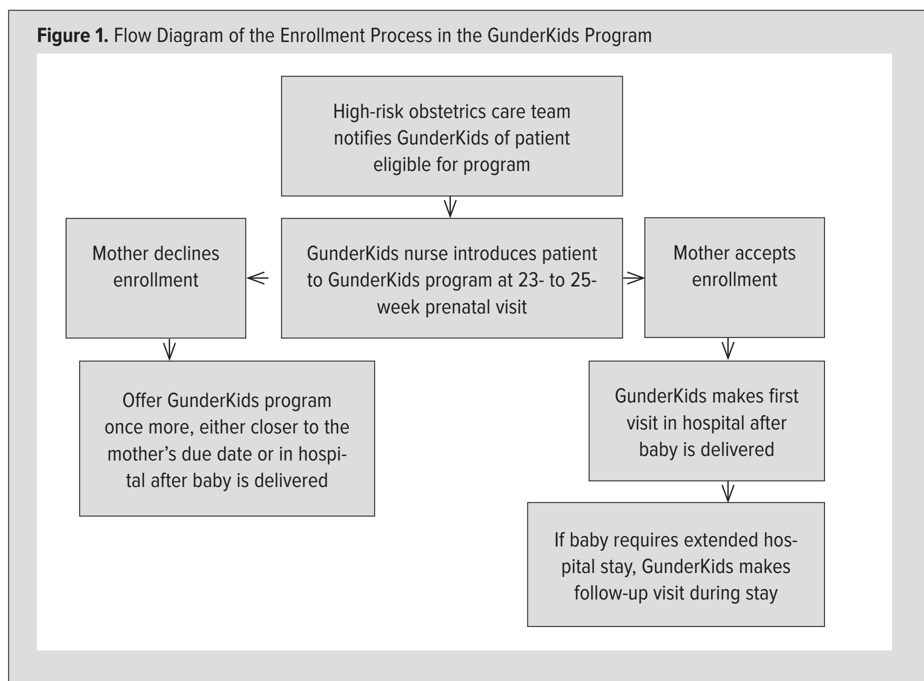
Figure 1. Flow Diagram of the Enrollment Process in the GunderKids Program

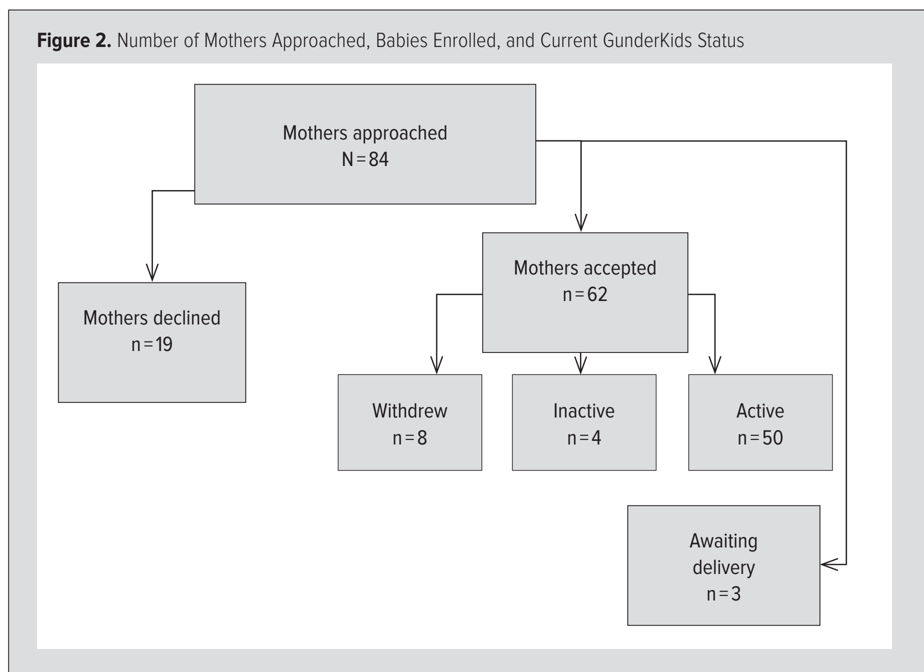
Figure 2. Number of Mothers Approached, Babies Enrolled, and Current GunderKids Status

Staff

GunderKids was initially led by a pediatrician and supported by 2 pediatric nurses, a social worker, and a child psychologist, who have since been joined by another pediatrician, another nurse, and a nurse practitioner. This level of staffing and consistency in who meets with the family is an innovative feature of GunderKids and important in developing and maintaining a trusting relationship with parents who are uncomfortable with other aspects of the social support system. GunderKids staff members all have training and interest in child health, well-being, and prevention of child maltreatment.

Medical appointments for the baby with the pediatrician and nursing staff are reimbursed through insurance. Funding for the family's time spent with the social worker and child psychologist, as well as nursing care coordination time, is provided by Gundersen Health System's pediatrics department.

Participants

GunderKids enrollment is voluntary. Women are approached by a GunderKids nurse during a prenatal visit around the 23rd through 25th week of pregnancy. They describe the type of support, education, and assistance available both through the clinic and in the community. Women who decline enrollment at the prenatal visit are approached again, either closer to their due dates or in the hospital after they have delivered (Figure 1). Figure 2 shows the number of mothers approached to participate in GunderKids and their current participation status.

A variety of concerns motivate parents to participate in a medi-

Box 2. GunderKids Schedule of Care—Clinic Visits, Activities, and Follow-up Telephone Calls

Once-a-Week Visits

Visit 1: Clinic Visit

Visit 2: Clinic Visit
- Newborn Behavioral Observations (NBO)

Visit 3: Clinic Visit
- Demographic Intake

Visit 4: Clinic Visit
- Caregiver Wellbeing Questionnaire

Visit 5: Clinic Visit
- Parenting Stress Index (PSI)

Every-2-week Visits and Every-Other-Week Telephone Calls

Telephone: Follow-up Call

Visit 6: Clinic Visit
- Child Abuse Potential Inventory (CAPI)

Telephone: Follow-up Call

Visit 7: Clinic Visit

Telephone: Follow-up Call

Visit 8: Clinic Visit
- Caregiver Satisfaction and Confidence Questionnaire
- Adverse Childhood Experiences (ACEs) Screening/Behavioral Health Integration

Telephone: Follow-up Call

Visit 9: Clinic Visit

Telephone: Follow-up Call

Visit 10: Clinic Visit

Telephone: Follow-up Call

Visit 11: Clinic Visit

Every-4-week Visits and Every-Other-2-week Telephone Calls

Telephone: Follow-up Call

Visit 12: Clinic Visit

Telephone: Follow-up Call

Visit 13: Clinic Visit

Every-6-week Visits and Every-Other-Month Telephone Calls

Telephone: Follow-up Call

Visit 14: Clinic Visit

Telephone: Follow-up Call

Visit 15: Clinic Visit
- Caregiver Wellbeing Questionnaire

Telephone: Follow-up Call

Visit 16: Clinic Visit
- Parenting Stress Index (PSI)

Telephone: Follow-up Call

Visit 17: Clinic Visit
- Caregiver Satisfaction and Confidence Questionnaire
- Child Abuse Potential Inventory (CAPI)

cally guided program. Initial motivations are fear of NAS withdrawal, fear of parenting without guidance, a desire to retain or regain custody of the child, or to demonstrate to authorities good parenting activities and a commitment to changing behaviors.

Care Plan

GunderKids is different from routine medical care. It provides more scheduled appointments during the first year of the baby's life. Visits occur within a medical clinic environment rather than in the mother's home, where she might feel vulnerable to officials entering her house. Parents can ask GunderKids for advice on parenting in a nonthreatening environment that allows for teachable moments. Clinic visits provide these families with trusted faces who are there for them consistently at each clinic visit and at any time between.

At each clinic appointment, the GunderKids nurse and social worker (1) review current stresses in the family; (2) improve the parent's knowledge of child development and child behavior; (3) discuss and give parents tools to deal with high-risk issues in child development; and (4) provide support and advise them of resources: food pantries, parent support groups, help with addictions, and housing options. Most of these parents have a history of trauma, which has adverse effects on mental and physical health. What's more, addiction is a chronic disease. Staff works with the family to break bad habits, such as the use of foul language, and to identify activities counterproductive to good parenting. Improving the health of the entire family is key to a healthy baby.

The desired appointment schedule and activities to be completed at each visit are provided in Box 2. Because these families often cannot keep scheduled appointments, the timing of activity completion varies. The GunderKids nurses follow up with the families by telephone and reschedule missed appointments. The team also works hard to accommodate those who present late to appointments or who appear at unscheduled times.

Our Experience

GunderKids is all about building relationships. After approximately 3 appointments, mothers become more positive and trusting of GunderKids. Their attitudes evolve from viewing the program as a necessary burden to maintain custody, to enjoying the relationship and trust that has developed with GunderKids staff—wanting to demonstrate how well they are doing and to learn more about parenting. Key to this trusting relationship is treating mothers with respect and caring and the continuity of care provided by the GunderKids team.

Future

Word about the GunderKids program traveled quickly. The Heroin Taskforce, School District of La Crosse, La Crosse County Child Protective Services, and La Crosse County Child Abuse Multidisciplinary team all requested presentations about GunderKids. If community response is any indication, need for programs like GunderKids is enormous, which challenges our capacity to accommodate all families who would benefit from enrollment. Therefore, we are prepared to present our results at medical conferences and to share our resources and experiences to assist other health care systems that desire to develop similar programs. Because the medical visits are reimbursed by insurance, the GunderKids model of care should be sustainable at most major medical centers. However, to fully implement the care plan, medical centers or other health care resources, such as Medicaid, will need to provide funding for the social worker, the behavioral medicine provider, and nursing care coordination time.

The success of the program as the initial pilot year progressed

indicated that planning would be required for continuation beyond the first year of life. The close relationships built with the GunderKids families and the team made it clear that the program should continue at some level for the rest of childhood.

Long-Term Benefits

Planned research projects will provide evidence regarding the short- and long-term value of GunderKids, which might encourage other health systems to establish similar programs. These research projects will compare the GunderKids program outcomes to those of other programs, such as stationing addiction counselors in child welfare offices, providing mothers priority access to substance abuse treatment slots, and home visitation programs.

The annual health care cost of child maltreatment and exposure to violence has been estimated at $333 billion to $750 billion, with the public and social cost deemed "incalculable."[9] Wisconsin is experiencing the same opioid epidemic as the rest of the country, as well as challenges with methamphetamine and other substances of abuse. The children of Wisconsin born into families with substance use disorder are at risk of maltreatment and neglect. Abuse prevention will lead to a healthier Wisconsin and save billions in health care dollars over time.

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