

Nutaqsiivik—An Approach to Reducing Infant Mortality Using Quality Improvement Principles

Marilyn Pierce-Bulger and Thomas Nighswander

The Alaska Native Medical Center, one of nine teams that participated in the Institute for Health Care Improvement's Community-Wide Learning Collaborative, used quality improvement principles to address a disparately high post-neonatal infant mortality in the Anchorage Native infant population. A unique concept, "Days Between Deaths," was used to measure mortality change for a small data set. Ongoing evaluation processes have demonstrated a fifty percent reduction in infant mortality and very successful approaches to care for high social risk women and their families.

Key words: Alaska Native, customer service, health disparity, infant mortality, PDCA cycles, program evaluation

THE ISSUE OF UNACCEPTABLY high infant mortality has been a pervasive problem that has been the subject of national attention for many years.^{1,2} Various strategies have been employed but the sad reality is despite rate improvements during the past 10 years,^{2,3} infants living in this country are still more likely to die before their first birthday than infants in 26 other industrialized nations. The most recent rate is 7.2 infant deaths per 1,000 live births.⁴

Of particular concern is the disparity between racial and ethnic groups in the U.S. Recent congressional legislation has directed the National Institutes of Health (NIH) to establish a center to study the reason behind higher rates of infant mortality (and other disparate health problems) in minority populations.⁵

In 1993, the Alaska Native Medical Center (ANMC) (formerly an Indian Health Service site now tribally operated) in Anchorage, Alaska, was invited to participate in the Institute for Health Care Improvement's Community-Wide Learning Collaborative. Teams from nine cities participating in this collaboration were trained to use quality improvement (QI) principles to address a public health problem. Each team was expected to seek community agency "partners" with whom they would address the selected issue. While each community selected a unique problem, they all used similar QI strategies for problem solving.⁶

ANMC staff chose post-neonatal infant mortality for Anchorage Natives because their death rate was three times higher than that for other Alaskan infant popula-

Marilyn Pierce-Bulger, FNP, CNM, MN, is a retired Captain in the U.S. Public Health Service and a health systems and clinical consultant in Anchorage, Alaska.

Thomas Nighswander, MD, MPH, Consultant, Anchorage, Alaska.

tion groups. An extensive review of 27 Anchorage Native infant deaths led to theories about how to address the problem. Community partners included Southcentral Foundation; the State of Alaska Division of Family and Youth Services; Women, Children and Infant's (WIC's) Supplemental Food Program; Municipality of Anchorage Community Health Nursing; and the Anchorage Police Department.

Flow charting techniques were used to evaluate how the ANMC "system" identified high-risk pregnant women and how it communicated between various departments such as obstetrics/gynecology (OB/GYN), pediatrics, emergency, mental health, and social services. Flow charts also explored how communication paths intersected with existing community programs that served the same high social risk women.

As gaps were identified and questions raised (as "cloud" icons on charts), ANMC staff used these points to target efforts for system improvements. Researchers very quickly learned the following:

- high-risk clients do not have the same priorities health care providers might have for them
- basic needs are unmet (food, shelter, safety)
- their sense of "time" does not lend itself to a "traditional" appointment system
- social isolation is striking
- lack of reliable transportation and child care are constant barriers to services
- communication challenges include lack of telephones and parental learning disabilities
- intra- and interagency service delivery and communication "systems" were not very effective with this client group

ANMC staff resolved that to be truly effective with high social risk families, they would have to be tenacious about their commitment to being flexible. A hospital-based community health nurse and nurse-midwife were given the opportunity to create Nutaqsiivik (a Yupik Eskimo word meaning place of renewal), which would work *in partnership* with its clients. Creativity was endorsed and ANMC staff delivered services to where clients were, both figuratively and literally, as needed. No new funding was used to create this program.

Social Risk Criteria for Nutaqsiivik Referral

- Homelessness
- Positive urine drug screen for mother or infant
- Maternal substance abuse during pregnancy or at risk for relapse postpartum
- Current maternal psychiatric disorder or depression
- Maternal FAS/FAE diagnosis or other cognitive impairment
- Age 16 or under
- Worrisome parenting behaviors
- "Provider Hunch"
- Prenatal care:
 - None
 - Onset in third trimester
 - Inconsistent or erratic care
- History of:
 - SIDS
 - Childhood sexual abuse
- Recent or current:
 - Domestic violence
 - DFYS (child protection system) involvement

Nutaqsiivik Program goals were to:

- promote safe home environments for high social risk infants
- provide client-centered, risk-based interventions that would support the high social risk family in efforts to move toward self reliance
- increase the ANMC system responsiveness to high social risk families
- increase Anchorage community partnerships and awareness of the program's goals and activities
- collect data and information to determine the nature and extent of need among high social risk Native families in Anchorage for program planning and evaluation

A standardized risk list was created to identify clients at high social risk during their pregnancies as these were the mothers whose infants were most at risk for post-neonatal mortality based on ANMC's reviews (see box titled "Social Risk Criteria for Nutaqsiivik Referral"). Nearly one third of ANMC's Anchorage Native prenatal patient population was found to be at high social risk.

A "one-stop shopping" clinic was created to provide convenient prenatal, neonatal, and postpartum care. The community health nurse conducted home visits on a scheduled and "as needed" basis until the infant reached 12 months of age. The in-home services included:

- infant and adult health assessment
- immunizations
- contraception (i.e., Depo-Provera injections, method change support, and counseling)
- anticipatory guidance regarding home and situational safety
- general support and advocacy
- case management and care coordination based upon client needs and desires
- transportation

Evaluation Methods

The Nutaqsiivik Program consistently has reevaluated interventions and analyzed client satisfaction and needs. Program evaluation has been conducted using several techniques. Especially challenging was finding a way to measure improved outcomes (decreased neonatal deaths) in a small cohort of patients.

Numerous rapid cycle interventions were instituted with simple evaluations using the Plan-Do-Check-Act (PDCA) model. For example, ANMC staff theorized that telephone call and letter reminders of appointments would increase appointment keeping behaviors and decrease the clinic "no show" rates. ANMC staff discovered the following:

- client telephone numbers were not a consistently reliable form of communication
- letter reminders came back to ANMC as undeliverable
- unreliable transportation was a major barrier
- clients *did* begin to call to say they couldn't get to the appointment so ANMC staff either could facilitate management of a transportation crisis or reschedule the appointment

What did ANMC staff learn? ANMC staff no longer use mail reminders. Telephone reminders are done by the community health nurse based upon her experience with the client, and transportation issues are planned for and dealt with during home visits. The "no show" rate *did* decrease (Figure 1) but not due to the interventions first theorized.

Chart reviews are another useful methodology. A review of previous Nutaqsiivik mothers and infants is

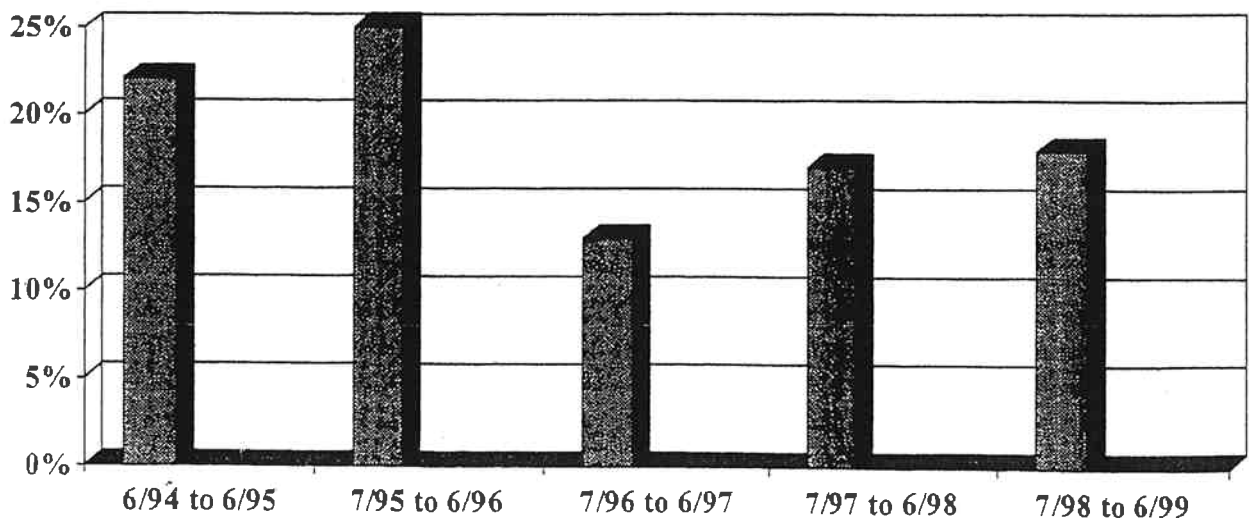


Figure 1. No show rates (WHS-Nutaq).

done annually to compare long term maternal and infant risk factors, health indicators such as immunization rates, contraception use rates, pregnancy recurrence rates (Figure 2), health care system utilization patterns, and trauma/accident incidents, to name a few. Aggregate information also is reviewed using the case management system (CMS) database to look for overall changes in risks.

Of note is the recent observation that 28% of the Anchorage Native high social risk mothers who ANMC is working with have diagnoses such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), or other behavioral or cognitive dysfunction that clearly interferes with their ability to parent successfully and independently. Based on each year's review findings, recommendations are made for intra- and interagency program development.

The tenets of customer service require that one "knows the customer" to be able to design an acceptable, successful service. ANMC customers, the high social risk client, had the characteristics as described above and over time, ANMC staff have learned more about their needs. Staff also learned that:

The tenets of customer service require that one "knows the customer" to be able to design an acceptable, successful service.

- 61% needed mental health services (only 16% were receiving them)
- 33% needed substance treatment (only 10% were in treatment)
- 60% lacked safe child care so that they could participate in needed services
- a clear pattern existed of clients being unable to meet goals established for them by various "systems" such as child protection, criminal justice, or public assistance

ANMC staff found recurrent examples (in its own system and in other agencies) of inflexible system entry points and intake processes that created barriers to care. Intake processes often missed the needs of the cognitively impaired client. "Long" waits to enter

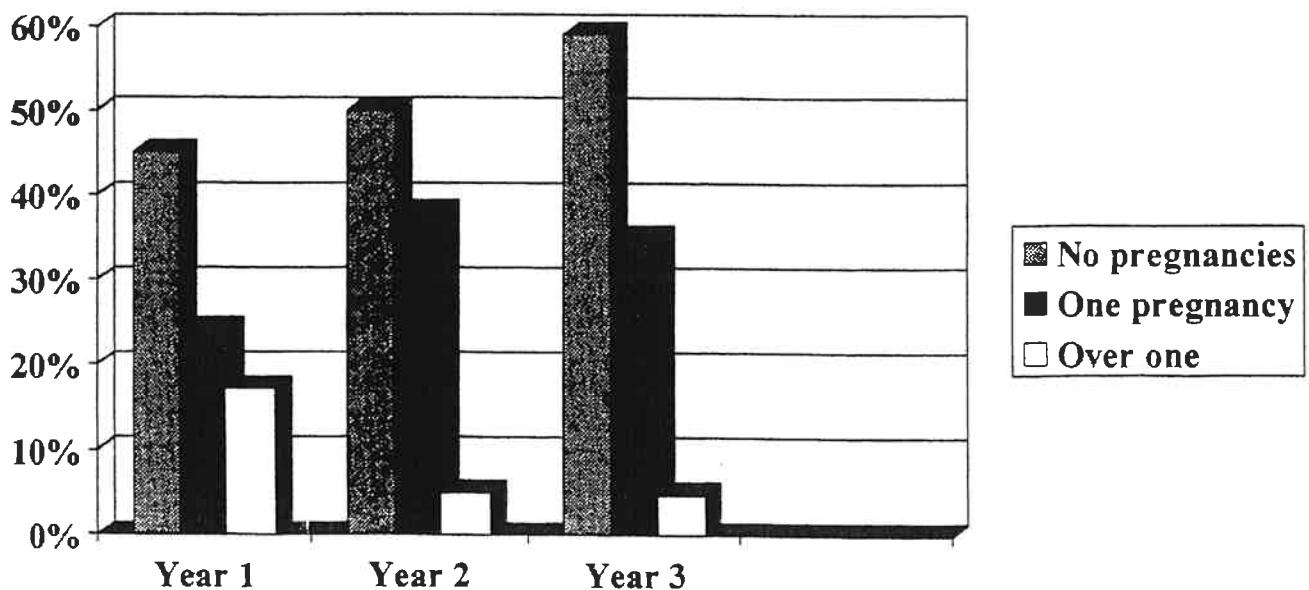


Figure 2. Pregnancy recurrence rates.

care or delays in service delivery created situations where "lower level" needs (shelter, food, or safety) may become a higher priority for the client. ANMC now proactively negotiates with "systems" to acquire the necessary service for its clients.

ANMC staff also learned to measure client success in small behavioral changes. For example, they may have:

- learned to call to say they can't come to clinic instead of being a "no show"
- experienced a longer interval between pregnancies or seek prenatal care earlier or more often
- demonstrated a willingness to problem solve about a contraceptive side effect
- consulted with the nurses for infant health concerns when the symptoms might have gone ignored or unreported in the past; this led to more timely evaluation and earlier treatment and intervention

The community health nurse's willingness to be nonjudgmental earned client trust and created a partnership atmosphere that these clients previously have not experienced in the health care system.

Client satisfaction is high as measured by satisfaction surveys and verbal compliments to staff. The ultimate compliment comes from the high social risk women referring their family and friends to this program.

New Measurement Concept for Public Health

While ANMC staff worked intensively with families on social and health risk issues, the overall aim of the project continued to be the reduction of post-neonatal infant mortality. The target group was the approximately 500 annual Native infants who lived in Anchorage. Even though their neonatal death rate was three times the national average, the actual number of deaths was only five or six per year. With these small numbers, ANMC staff had to find a way to determine if a program change was an improvement.

The tool in use is the "Days between Deaths" run chart, which was developed during the start-up phase of the project with the assistance of Tom Nolan, PhD, of Associates in Process Improvement. His theory for

small number data sets was to borrow the concept of charting days between events used in industry (i.e., days between accidents in a manufacturing plant). ANMC created a baseline (benchmark) run chart of days between deaths for Anchorage Native infants age 1 to 12 months for the 5 years prior to the onset of the Nutaqsiivik Program. "Days between Deaths" moved from a pre-program average of every 55 days to an average of 114 days since clinic and home visiting services began in June 1994 (Figure 3). In this run chart, the y axis is the number of days and the x axis records the dates of the post-neonatal infant death. The higher spikes represent a more successful outcome.

ANMC adds Anchorage Native infant deaths as they occur and recalculates "days between" with each new data point added. If the family has had care in ANMC's health care system, staff conduct a review of the deceased infant's medical record as well as sibling and parent medical records to look for variables or patterns that would be useful for future care planning or prevention activities. In the case of infants with whom ANMC staff may have been involved, ANMC has the added benefit of supporting the family after the loss.

ANMC now has 10 years of run chart data and is able to create a more visually meaningful "Annual Days between Deaths" chart as well (Figure 4).

Evaluation Information into Action

Early flow charts identified "clouds" between various departments and agencies and follow-up flow charts were used to assess the impact of ANMC's system changes. More often than not, researchers found old gaps closed but new questions raised. Staff used numerous PDCA cycles to explore strategies. Service improvements have included:

- dictating social history summaries that are specifically for pediatric provider use
- creating a Pediatric Nutaqsiivik Clinic for longer continuity of care
- improving communication between child protection providers and community health nurses
- increasing involvement in community agency planning and care coordination activities