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Successful Ways to Increase Retention in a Longitudinal Study of Lead-Exposed Children

Much has been written about low retention rates in longitudinal studies of children (Bender, Ilke, DuHamel, & Tinkelman, 1997; Hartsough, Babinski, & Lambert, 1996). Although no reports on retention rates in studies of lead-exposed children were found, other clinical trial studies reported varied retention rates. In a review of clinical studies following children with ADHD into adulthood, Klein and Mannuzza (1991) reported retention rates of 51 percent to 88 percent. Other authors reported retention rates ranging from 75 percent (Tinkelman, Reed, Nelson, & Offord, 1993) to 81 percent (Hartsough et al.,1996). Reasons given for these retention rates include the length of the commitment required, participants' distrust of research programs, and family stresses (Bender et al., 1997). Loss of any subject can affect the statistical power of the findings, possibly leading to erroneous conclusions. Thus, it is important to retain as much of the original cohort as possible.

The Treatment of Lead-Exposed Children (TLC) study, was a multiyear National Institute of Environmental Health Sciences contract carried out in four urban sites: Newark, NJ; Baltimore, MD; Philadelphia, PA; and Cincinnati, OH. Its purpose was to study the effects of oral chelation on the neurobehavioral sequelae of lead exposure in children with low to moderate lead levels (20–44ug/dl). The study enrolled 780 children ages 12 to 33 months. It consisted of a randomized, placebo-controlled, double-blind trial of up to three courses of treatment with succimer (a lead chelating agent) and required frequent visits over a period of three years.

The Newark TLC site, located at the University of Medicine and Dentistry of New Jersey (UMDNJ), enrolled 208 children, of whom 71 percent were African American, and 22 percent were Latino/Hispanic. Of the enrolled children, 101 were girls and 107 were boys. Almost all were residents of urban areas with deteriorating housing. The Newark TLC site maintained a 97 percent retention rate (attrition rate of 3 percent) over a five-year period. Retention rates for the other three TLC sites ranged from 84 percent to 95 percent. This article describes the four primary factors that contributed to Newark TLC's high retention rate: program structure, social work resources, family care, and tangible supports.

Factors in High Retention Rate

Program Structure

Staffing made a significant contribution to the low attrition rate at the Newark site. On the basis of decades of experience working with urban lead-exposed children, one of the principal investigators decided to hire personnel dedicated to the project rather than use staff from other hospital departments. Clinical staff consisted of one pediatric advanced practice nurse, one registered nurse, two pediatricians, a bilingual social worker, a bilingual social work aide, a supervising psychologist, and a bilingual psychologist.

Using University Hospital in Newark as home base, TLC Newark also operated clinics in a nearby city's health department and at a satellite outpatient clinic 40 miles away. TLC Newark staff traveled to all three sites, so that families were assured that the same staff would always greet them, know their history, and care for their needs on each visit.

All TLC staff were hired three to six months before recruitment of study participants.

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Regardless of prior experience and training in working with lead-exposed children, all staff received at least three months of training in the UMDNJ Pediatric Lead program.

Social Work Resources

The presence of a dedicated bilingual social worker was a key component of Newark's retention success and was unique to the Newark TLC site. The social worker provided a vital link between the study and the enrolled families. The most critical elements of this role were home visits, missed appointment follow-ups, referrals to ancillary services, hands-on assistance, and managing and providing transportation to and from clinic visits.

The social worker's participation allowed for immediate response to missed appointments, frequently by means of home visiting. Consistent follow-up on these appointments provided reliable information about families who had moved, did not want to continue in the program, or were experiencing personal problems that interfered with keeping clinic appointments. In the event that the social worker could not locate the family, their whereabouts were researched through local social services agencies. As a result, only three families were completely lost to the study, although many families moved or experienced significant disruptions and life crises (for example, parental death, imprisonment, fires, drug treatment, and foster care) over the course of the study.

Many Newark TLC families had chronic problems with inadequate transportation, housing, and health insurance coverage, as well as cultural, legal, and language barriers. TLC Newark realized that these problems had the potential to interfere with consistent participation in a multiyear program. The decision was made to allocate a significant amount of the social worker's time to helping families obtain critical services unrelated to the TLC program. Referrals were made for housing, welfare, food pantries, immigration services, and early intervention services for children. In many cases, the TLC social worker accompanied families to necessary appointments. Baby-sitting was provided or money was given for the home care of siblings while the TLC child attended the clinic. By providing tangible support and assistance, TLC facilitated families' emotional loyalty and ensured continuous participation in the program.

Attendance at clinics is a pivotal practical problem for a population the majority of whom lacks access to cars and depend on an inadequate public transportation system. The TLC social worker assumed responsibility for arranging transportation to and from the clinic for all children's visits. When local transportation companies were unreliable or unavailable, the social worker picked up the families.

The social worker and social work aide were first generation Americans who were familiar with and understood the difficulties faced by TLC's Latino families. They used the nontraditional personalized approach recommended for relating to Latino families by actively engaging the client and even sharing some personal information (Acosta & Evans, 1982). They translated for mothers when forms needed to be completed or letters written in English to obtain services. When necessary, the social worker accompanied Latino families to appointments in the community to ensure that their needs were understood and met. Many TLC Newark families became very attached to the social worker and actively sought help with personal problems.

Family Care

The success of any longitudinal study involving adherence to a medical regimen is related to the degree to which the participants understand its time and attendance requirements (Fotheringham & Sawyer, 1995). Newark staff frequently reviewed the study protocol and time commitments with enrolled families. Caregivers were assured that they could end their involvement in the program at any point. These frequent reminders appeared to help participating families become more committed to completing the program.

Research has shown that the quality of relationships between clinic staff and families are important to the success of any commitment to medical treatment (Fotheringham & Sawyer, 1995). Despite the fact that TLC was a research study, TLC Newark staff made it an explicit priority to maintain professional, yet committed relationships with families in the study. Information about relevant life events of participating families was shared among staff at regularly scheduled meetings to ensure that everyone was informed of needs for help and support. Great effort was made to understand each family's situation and to develop an appropriate plan for

family care beyond the protocol mandated by the study. It was also important for the integrity of the study and for the child's continuity of medical care for TLC staff to keep the child's primary care or referring physician informed about the child's lead status, as well as any interventions or referrals made by TLC.

Sensitivity and flexibility in scheduling appointments for families are particularly fundamental for a longitudinal program. Often, clinics give a single appointment (such as 9 A.M.) to all families due that day, forcing families to wait indefinitely to see medical personnel. TLC Newark families were given appointments at specific times and were seen as soon as possible after they arrived. When families came late or after clinic hours, staff completed the appointment instead of rescheduling the visit. Over time, families became accustomed to TLC's scheduling policies and responded by arriving increasingly on time for appointments.

Standard nine-to-five clinic hours were problematic for many working parents and for those who did not want their children to miss school. In addition, many TLC Newark families were participating in the "Welfare-to-Work" program and would be penalized if they missed training sessions. TLC Newark diligently accommodated families' schedules, which sometimes included making evening or weekend appointments. Often this required sending a cab for the family or picking them up.

Tangible Supports

TLC incorporated a number of tangible supports, during clinic visits and interim periods, which helped to retain even the most recalcitrant families. For example, the child's blood was drawn at almost every clinic visit. To make this less traumatic, staff included the child in making decisions such as whether to sit up or lie down during the blood draw and choice of Band-Aid. Although this may sound simplistic, it helped ease the child and parent's apprehension regarding the anticipated pain of the blood draw.

The TLC program also included a bilingual environmental team trained in U.S. Department of Housing and Urban Development standards and familiar with the local community. This team inspected each home, performed lead reduction cleanup, and educated the families about home lead hazards. They demonstrated appropriate lead-cleaning techniques (such as wet rather than dry mopping) and gave each family free cleaning supplies for maintaining a lead-safe home. The environmental team's visits helped in retention, because free house cleaning by professionals was very desirable to many families. In addition, they provided additional opportunities for staff to make contact with families between clinic visits.

With up to four months between required clinic visits, interim contact was vital to keeping families in the program. Twice a year all families were invited to special celebrations, including a winter holiday party and a summer picnic. Holidays and special occasions were remembered by TLC staff both at clinic visits and by means of home visiting. For example, during Black History Month, coloring and activity books depicting important African Americans were distributed to families. During Valentines' Day and Halloween, goody bags were given to the children. On Mother's and Father's Days, TLC gave the children small gifts to give to their parents. Children received puzzles and books on their birthdays, and birthday cards were sent to parents (Many parents appreciatively told staff that the TLC card was the only birthday acknowledgment they received). During difficult times, such as when a child or family member was ill, a visit was made to the home or hospital. When there was a death in the family, TLC staff attended the funeral or made a home visit with a fruit basket.

An important aspect of TLC clinic visits resulted from an off-hand suggestion by a staff member. One day a staff member brought in a box of little gifts for the parents. The box was filled with books, pens, toiletries, and other items parents might enjoy. The parents liked the gift box so much that staff decided to name it the "Mommy Box," because most of the children were brought in by their mothers. On each visit, parents eagerly looked through the box to see what new goody awaited them. Because of its popularity, the Mommy Box was used for the length of the study.

Conclusion

Lead exposure is a silent disease. It is invisible, and most affected children are asymptomatic. Given these dynamics, it took ingenuity and persistence to maintain families in the TLC program, especially given that most had life issues such as homelessness, loss of public assistance,

domestic violence, and foster placement that impinged on their continued participation. The techniques discussed in this article contributed to Newark TLC's retention success and can be generalized to any program trying to maintain long-term contact with families. HSW

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