Public Health Nursing Vol. 23 No. 3, pp. 205–215
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POPULATIONS AT RISK ACROSS THE LIFESPAN: EMPIRICAL STUDIES

Guiding Mothers' Management of Health Problems of Very Low Birth-Weight Infants

Karen A. Pridham, Mary M. Krolikowski, Rana K. Limbo, Jill Paradowski, Nancy Rudd, John R. Meurer, Ann Uttech, and Jeffrey B. Henriques

ABSTRACT ***Objective:*** Explore the feasibility, usefulness, and outcomes of a pilot program to support mothers in developing competencies for managing health problems of their very low birth-weight (VLBW) infants in partnership with the primary care clinician (PCC). ***Design:*** In a randomized study, mothers who received guided participation (GP) and printed guidelines for managing VLBW infant health problems were compared with mothers who received only the guidelines and standard care (GL group). ***Sample:*** All mothers (GP = 20; GL = 11) were at least 18 years old and English speaking. Infants were all VLBW ($\leq$ 1,500 g). ***Intervention:*** GP began during the infant's neonatal intensive care unit stay and continued with public health nurses (PHNs) and a family service clinician through the infant's first 4 postterm months. ***Measurements:*** Intervention feasibility and usefulness were assessed with maternal and clinician feedback. Outcomes included maternal and clinician appraisal of mothers' use of clinical resources and mothers' perceptions of primary-care quality and the family-PCC relationship. ***Results:*** Intervention feasibility and usefulness were supported. GP and GL groups did not differ significantly on outcomes. ***Conclusions:*** Findings indicate a longer intervention period, GP organized by infant problem episodes, and enhancement of the PHN role in the context of interdisciplinary and interagency collaboration.

Key words: guided participation, health problems, maternal competency, premature infants.

Karen Pridham, Ph.D., R.N., F.A.A.N., is a Helen Denne Schulte Professor of Nursing Emerita, School of Nursing and Department of Family Medicine, University of Wisconsin-Madison, Madison, Wisconsin. Mary M. Krolikowski, M.S.N., R.N., P.N.P., is a Research Nurse at the Herma Heart Center, Children's Hospital of Wisconsin, Milwaukee, Wisconsin. Rana K. Limbo, Ph.D., R.N., is Director of Bereavement Services, Gundersen-Lutheran Medical Foundation, La Crosse, Wisconsin. Jill Paradowski, M.S., R.N., is a Healthcare Outreach Coordinator, City of Milwaukee Health Department, Milwaukee, Wisconsin. Nancy Rudd, M.S., R.N., P.N.P., is a nurse practitioner in the Herma Heart Center, Children's Hospital of Wisconsin, Milwaukee, Wisconsin. John R. Meurer, M.D., M.M., is a Medical Director, Downtown Health Center, Children's Hospital of Wisconsin, Milwaukee, Wisconsin, and Associate Professor and Chief of General Pediatrics at the Medical College of Wisconsin, Milwaukee, Wisconsin. Ann Uttech, M.S., L.M.F.T., is a family therapist at Aurora Family Service, Milwaukee, Wisconsin. Jeffrey B. Henriques, Ph.D., is a Senior Lecturer and Associate Researcher, School of Nursing and Department of Psychology, University of Wisconsin-Madison, Madison, Wisconsin.
Correspondence to:
Karen Pridham, School of Nursing, University of Wisconsin-Madison, Clinical Science Center, H6/293, 600 Highland Ave., Madison, WI 53792. E-mail: kpridham@wisc.edu

Mothers' concern about managing their infants' minor, acute, or self-limiting health problems is likely to begin early and in anticipation of actual problems. During their postpartum stay in hospital, mothers of healthy term infants expect to learn about signs of illness and about when to call the pediatrician (Callaghan, Greenberg, Brasseux, & Ottolini, 2003). The need to manage infant health problems is likely to be an early reality for mothers of very low birth-weight (VLBW) infants (i.e., infants weighing less than 1,500 g at birth). In a research study, health problems were most often the reason that parents of VLBW infants initiated telephone calls to project nurses for assistance (Brooten et al., 1986).

Maternal competence in managing health problems is critical to the well-being of VLBW infants whose immature systems and vulnerability to physiologic instability require attentive and informed monitoring, timely and sensitive response, and clear communication with the primary care clinician (PCC). Because PCCs rely on mothers' observations and responses to effectively support the infant's health, problem management requires a partnership of mothers and clinicians (American Academy of Pediatrics, 2002; Institute of Medicine 1996, Lawhon, 2002; Simpson et al., 2004).

Although mothers of VLBW infants receive instructions about prevention of infections and care of minor acute illness before discharge from the neonatal intensive care unit (NICU) (Gamblian, Hess, & Kenner, 1998), they are likely to be unprepared for managing acute and, in general, self-limiting health problems (e.g., fever, constipation). These mothers may need greater skill in communicating and joint problem solving with PCCs often required for home management of acute health problems.

Neither clinical nor research literature has addressed the competency of mothers of VLBW infants in managing health problems after the infant's NICU discharge. Nor has the primary care experience in the context of these health problems been explored from the perspective of both mothers and the infants' PCCs after the infant leaves the NICU. An expected outcome of helping mothers learn to participate in managing health problems of their VLBW infants is greater maternal competency in using clinical services and health-care resources compared with that of mothers not receiving intervention (Institute of Medicine, 2001). In addition, guidance for mothers in managing VLBW infant health problems in collaboration with PCCs could be expected to result in higher evaluation of the quality of the relationship with the PCC and better access to and quality of primary health care for the infant (Institute of Medicine, 2001). Qualities of the family-PCC relationship associated with family-centered and culturally sensitive care include clarity of communication, understanding of and appreciation for family perspectives and needs, and involvement of the family in problem solving and decision making that is sensitive to the family's desires and goals (Van Riper, 1999, 2001).

The purpose of this paper was to explore the feasibility, usefulness, and outcomes of a pilot interdisciplinary and interagency program to support mothers in developing competencies for managing health problems of VLBW infants through their first 4 postterm months. In addition to competencies in using clinical services and health-care resources, we examined, as outcomes of the nurse-provided intervention, mothers' evaluation of the quality of their relationships with the infant's PCC and of the infant's primary care.

Health problems in VLBW infants and family management

Prematurity is a public health concern owing to the high risk for mortality and morbidity associated with it (AJN Reports, 2004; Burns, 2005). In particular, VLBW infants have more acute-care visits and hospitalizations than expected of healthy infants born at term (Brooten et al., 1996; Elixhauser et al., 2002; Termini, Brooten, Brown, Gennaro, & York, 1990). Little is known about family management of health problems in partnership with clinicians or of family experience with nonacute health problems (e.g., constipation, spitting up) that may or may not be brought to a PCC's attention.

On the whole, mothers are acknowledged as first-line decisionmakers concerning an infant's health problem (Dahlquist, Sterky, Ivarsson, Tengvald, &Wall, 1987; Parmelee, 1989). However, the published literature about interventions to aid mothers or other family members in managing these problems primarily concerns healthy infants. In a randomized repeated measures study, an educational brochure and video increased the knowledge of parents and grandparents in managing fever in young children beyond that of parents and grandparents who neither received the brochure and video nor had an opportunity to ask questions about content in the clinic (Broome, Dokken, Broome, Woodring, & Stegelman, 2003). Families of children enrolled in Head Start who received a self-help book on common childhood medical problems and training in its use made significantly fewer visits or calls to the doctor and significantly fewer visits to the emergency department for their children 6 months after training and reported greater confidence in their own decision making (Herman & Mayer, 2004).

Emphasis on family self-reliance in managing common acute illness and nonacute health problems may be misplaced for VLBW infants. These infants generally require more attention from clinicians when ill than healthy infants and children who are less vulnerable to physiologic instability. Decreased use of health-care resources may not be an appropriate outcome of intervention or an informative indicator of parental competency in managing a VLBW infant's health problems at home. Furthermore, parents require educational materials specific to premature infants in light of the physiologic fragility of VLBW infants and consequent need for more conservative management than is needed by a healthy term infant. Mothers of VLBW infants may need more in-depth, personalized, and ongoing guidance to competently monitor and assess health status, respond appropriately, and effectively communicate with clinicians than was provided in the reviewed interventions.

Guided participation (GP) for maternal competency development

Through GP processes, a less experienced person is guided by a more experienced or seasoned person in engaging, thinking, and performing beyond what could be accomplished without assistance (Vygotsky, 1978). Families, through GP, may acquire needed confidence and competencies and take on appropriate responsibility for managing VLBW infant health problems (Pridham, Limbo, Schroeder, Thoyre, & Van Riper, 1998; Rogoff, 1990, 1993, 2003). Competencies for managing health problems of VLBW infants may be developed through GP, which involves a partnership of inexperienced and more experienced or seasoned persons (Pridham et al., 1998; Rogoff, 1990, 1993, 2003).

The usual brevity of health supervision and health problem visits and the limited opportunities clinicians have to learn about what mothers expect or intend concerning health problem management limits their ability to help mothers work with them. Callaghan et al. (2003) recommended that pediatricians ensure that other sources of information for families such as nurses and media are available to supplement what they can provide. Both NICU nurses, during an infant's special-care nursery stay, and public health nurses (PHNs) in agencies that target at-risk children as a population in need of health promotion and illness prevention services (Keller, Strohschein, Lia-Hoagberg, & Schaffer, 1998; O'Brien, 2003) are well positioned to provide guidance for caregiving com petency development along with PCCs and clinic nurses. Working in concert with PHNs, family service clinicians (FSCs) who are prepared to assist families with mental health issues, procurement of needed resources, or relationship issues could explore with mothers their goals and problems in working with PCCs and support them in developing competencies in communicating and problem solving. Little has been made to date of a PHN role with the population of VLBW infants in promoting their health and lessening the impact of health problems on them. This type of role, however, would be consistent with PHN population-focused practice (Quad Council of Public Health Nursing Organizations, 2004).

Development of a GP program

In Milwaukee, the high rate of premature births in comparison with state and national rates (March of Dimes, 2005; Martin et al., 2003; National Center for Health Statistics, 2003) resulted in the Milwaukee Health Department (MHD) making this population a priority. One strategy was to link PHNs with NICU staffs and PCCs for continuity of care and to create more substantial PHN roles with families (Keller et al., 1998). Aurora Family Service of Milwaukee had mounted new programs for these families who were often at high social risk. Five PHNs and six Milwaukee NICU nurses had just completed a certificate, continuing education course on GP with families of VLBW infants. The clinical practicum included PHN, NICU nurse, and FSC collaboration (Pridham, Limbo, Schroeder, Krolikowski, & Henriques, in press). PHN observations of infant health problems and of family difficulties in communicating and problem solving with PCCs highlighted family health problem management as an underdeveloped area of nursing practice. Although guidelines on family management of VLBW infant health problems in partnership with PCCs were available to PHNs and NICU nurses, a plan for using the guidelines with families was not in place. These guidelines (Anderson, Rudd, Wiseman, Meurer, & Pridham, 2003) for breathing difficulty, constipation, prevention of dehydration, diarrhea, fever, spitting up, and vomiting included problem signs, appropriate family response, when to contact the PCC, and provision for the PCCs instructions and requested follow-up. These guidelines, drawn from relevant literature and clinical protocols, were reviewed by three primary care pediatricians and two advanced practice nurses before their use with families.

MHD and Family Service interest in strengthening support for families of premature infants led to the design and pilot test of an interagency program of GP beginning before an infant's NICU discharge and continuing through the first quarter year, postterm age (PTA). The aims of the study were to explore (1) the feasibility of collaboration of NICU nurses, PHNs, and an FSC in aiding families in effectively managing VLBW infant health problems through a GP program that included guidelines for health problem management, (2) the usefulness of the guidelines, and (3) the difference the GP program made, compared with the use of the guidelines alone (GL program) for maternal competency in managing infant health problems and for maternal perception of the quality of the infant's primary care and the family-PCC relationship.

Methods

In this longitudinal pilot study, mothers were randomly assigned to either the GP or the GL group. The academic and participating hospital institutional review boards approved the study. All PHNs, the FSC, and parents of premature infants signed statements of informed consent before providing any data.

Participating families and PCCs

Milwaukee families were recruited to the study from May 2001 through February 2003 by a project nurse who regularly reviewed eligibility with NICU nursing staff of each of four Milwaukee area hospitals. Eligible mothers were at least 17 years old and English speaking and reading, and had infants who weighed 1,500 g or less at birth, were appropriate weight for gestational age (Alexander, Himes, Kaufman, Moor, & Kogan, 1996; Ballard et al., 1991), and were free of congenital or chronic conditions other than bronchopulmonary dysplasia (BPD), which is diagnosed at 36 weeks post-conceptional age (Bancalari, Claure, & Sosenko, 2003). A computerized randomization method (Pocock & Simon, 1978) kept the GP and GL groups equivalent on infant gender, maternal race or ethnicity (African American, other minority, Euro-American), formal education (high school or less, more than high school), and type of milk feeding planned (breast, formula). All of the infants were completely nipple fed (breast or bottle) when discharged from the NICU. The infant's PCC (physician or nurse practitioner) and clinic registered nurse (RN) were each sent a copy of the guidelines and a letter explaining study participation and recommended guideline use with the PCC. Mothers were introduced to the guidelines by the project nurse who enrolled them in the study.

GL and GP programs

All families in both the GL and GP programs received usual community-based care for families with infants at medical risk including—in addition to primary care—PHN health assessment and support of well-baby care and immunizations. For mothers in the GL group, no further reference was made to the guidelines after their introduction unless by an NICU nurse or PCC in response to a mother's question.

Mothers in the GP group, in addition to usual PHN services, received protocol-directed guidance on managing VLBW infant health problems from one of four PHNs who had completed the GP course and family support from an FSC. After assignment to a family by the PHN nurse supervisor, the PHN made a NICU visit to the family, discussed with the family and the infant's NICU nurse plans for medical care and anticipated health issues, explained PHN/GP services, and made plans for a home visit within a week after the infant's NICU discharge. The FSC also met with the family during the infant's NICU stay and explained the family support services (i.e., resource procurement, care coordination, family relationship support, or mental health therapy). Both the PHN and FSC explained their collaboration with each other and intent to support family partnership with the infant's PCC. NICU nurses who had taken the GP course were requested to aid mothers in getting acquainted with the guidelines during the infant's NICU stay.

At least two GP protocol-guided home visits, one within 3 weeks of NICU discharge and the second before the end of the 4th month, PTA, were independently made by the FSC and PHN. At each of these visits, infant health issues on the mother's mind and problems that had occurred or were anticipated were explored with reference to what had been or could be useful in the guidelines and how the PCC had been or could be involved. The PHN encouraged anticipatory problem solving with a hypothetical situation, e.g., "Let's say that your baby wakes up at 04:00 a.m. and feels warm when you touch her. She is not interested in feeding. When you take her temperature under her arm pit, the thermometer reads 100°F. What would you do?" The discussion that followed would include signs of a fever, principles of responding to signs, when to call the PCC, and how to be prepared to answer questions the PCC was likely to ask. PHNs took the PCCs' role to support maternal competency in communicating with the PCC by asking questions about the baby's condition, what the mother had done, and the baby's response. Both the PHN and FSC supported mothers in raising questions concerning infant health and care; learning the most effective and efficient ways of contacting the PCC; expressing a point of view that differed from that of the clinician; contributing ideas to decision making and to plans for care; and assessing how well the plan was working.

The FSC explored, at each visit, health-care access, how infant well-child and acute illness care had gone; how well the mother thought the PCC had listened to her; and what could make visits with the PCC go better. Strategies for achieving goals were developed, and progress in collaborating with the PCC was reviewed.

GP program implementation and protocol monitoring

The PHNs, their supervisors, and the FSC met with the project nurses to discuss and revise a draft of the study protocols before family enrollment began. Thereafter, this group met approximately quarterly to explore family and PCC response to the guidelines, and refine and clarify the protocols as indicated. Throughout the study, a project nurse monitored protocol implementation through home visits made jointly with each of the PHNs and the FSC to two or more families each. PHNs, in addition to their usual family records, kept a log for the project of time spent with a family, either in person during a home visit or on the telephone.

At each family's completion of the study, PCCs and clinic RNs were mailed a brief form requesting feedback on the guidelines and the family's participation in the GP program. At the conclusion of the study, clinic RNs were telephoned by a project nurse about the use and development of the guidelines. Mothers evaluated the usefulness of the guidelines (GL group) or of the GP program (GP group) with a self-report form and response to a project nurse's telephone interview.

Data collection procedure

Data were collected three times by a project nurse who was blinded to family group assignment, first in the NICU after family study enrollment and again in the home at the end of the infant's 1st and 4th postterm months. Mothers appraised their competency in managing infant health problems at 1 and 4 months infant PTA. Appraisals of this competency were solicited from PCCs, clinic RNs, PHNs, and the FSC at 4 months infant PTA. Mothers' perceptions of the quality of the infant's primary care and of the family-PCC relationship were obtained at 4 months infant PTA.

Descriptive data sources. Data to describe the sample included the infant's perinatal medical history and primary care history, including acute-care visit, emergency department, and hospital admission data. Both hospital and primary-care clinic records were abstracted by a project nurse after the infant's 4th postterm month. Three of the records were audited by a second project nurse with at least 90% agreement.

Descriptive data also included self-reported family attributes obtained at the first data collection visit after written consent to participate had been given. Maternal responsibilities and social network were assessed at each of the three data collection visits. The social network report included the persons who helped with the baby's care either when the mother was at home or away, as well as with problem solving, emotional affirmation, and material goods. The social network instrument included a five-point scale to assess ease of obtaining help for each help source, with end points (1 and 5) marked *not at all easy* and *very easy*, respectively.

Sources of data to describe intervention outcomes: maternal competency in using clinical services and health-care resources to manage infant health problems. Both clinicians and mothers assessed this competency. We obtained clinicians' assessments with seven items developed from the input of PCCs and explored in earlier research studies (Pridham, 1987; Pridham, Chang, & Chiu, 1994). Competencies assessed included (a) communication clarity, (b) timeliness of problem presentation, (c) attention to important things, (d) problem management, (e) plan follow through, (f) clinical resource use, and (g) judgment in making contacts. End points for each of these items were labeled as follows: 1 = *not at all competent*; 6 = *very competent*. In addition, maternal problem-solving ability was compared with that of other mothers. The end points for this single item were 1 = *much poorer*; 6 = *much better*. For this study, the α coefficient for the eight items was 0.84.

Mothers assessed their own competence in working with PCCs with five items that mirrored the clinician assessment and with four additional items that addressed the following issues: (a) a mother's tendency to contact the clinic when the baby has a health problem; (b) a mother's belief that she makes a difference in the health care the baby received; (c) ability to do the right things when the baby was sick; and (d) attempt to be a partner with the baby's PCC. A 4-point scale was used for the maternal assessment (1 = *strongly disagree*; 2 = *disagree*; 3 = *agree*; 4 = *strongly agree*). The α coefficient for 51 assessments (1- and 4-month administrations, combined) was 0.83.

Other outcome data sources: Family-provider relationships. We used a 20-item modification of the Family–Provider Relationships Instrument-NICU (FAMPRO-NICU/Van Riper, 1999, 2001) to assess maternal perceptions of the quality of the PCC's relationship with the family in respect to task accomplishment, role performance, communication, affective expression, affective involvement, control, and values and norms. Mothers used a 4-point scale (1 = *strongly disagree*; 2 = *disagree*; 3 = *agree*; and 4 = *strongly agree*) to rate the extent to which a statement (e.g., "Our baby's primary-care provider encourages us to talk openly about things that bother us") described the relationship with the PCC. The study α coefficient was 0.83. FAMPRO-NICU construct validity was supported by Van Riper's (2001) finding that mothers of preterm infants with higher scores reported greater willingness to seek help from the clinician.

Outcome data sources: Mothers' perceptions of the quality of the infant's primary care. We used the 21-item instrument, Parent's Perceptions of Primary Care (P3C; Seid et al., 2001), to obtain mothers' reports of the quality of six components of primary care: (a) longitudinal continuity; (b) access; (c) communication; (d) clinician knowledge of the family (e.g., values and preferences); (e) comprehensiveness; and (f) coordination. P3C items, rated on a 5-point scale (0 = *never*; 1 = *sometimes*; 2 = *often*; 3 = *almost always*; 4 = *always*), have demonstrated high internal consistency and validity (Seid et al., 2001; Varni, Seid, & Kurtin, 2001). In this study, the four coordination of care items were rated by many mothers as not applicable and, therefore, were not included in the internal consistency study. The α coefficient for the 17 remaining P3C items for 23 responses was 0.74. Omission of the item concerning the availability of the doctor as soon as wanted for routine care would have raised the α coefficient to 0.79.

Analyses. For all instruments, item scores were summed and a mean score was obtained. We used an exact probability test (Good, 1994) to assess group differences.

Results

Description of the groups and sample

Twenty-three families were assigned to the GP group and 14 families were assigned to the GL group. Data were not collected for two GP group families whose infants were too ill to be cared for at home. One family in the GP group and three families in the GL group dropped out of the study or could not be contacted, making a sample of 20 mothers in the GP group and 11 mothers in the GL group who continued through the infant's fourth postterm month.

Groups did not differ significantly on any of the family, maternal, or infant condition variables. At birth, infants averaged 27.5 weeks of gestation (*SD* = 1.9) and weighed 981.9 g (*SD* = 274.4). Almost 57% of the infants had a diagnosis of BPD. On average, infants spent almost 77 days in the NICU (*SD* = 33.6). Approximately 55% of the mothers were primiparae. About 52% were married or living with a partner; 23% lived alone with their new infants. The remainder of the mothers (about 15%) lived with their own mothers. About 48% of the families had incomes below the federal poverty level. Almost 50% of the mothers were not employed during the 4-month study period; about 23% worked 40 hr/week. Eight of the 31 mothers were taking training courses, attending college, or completing a high-school equivalency degree during the study period. Four of these eight mothers were concurrently employed. Only 16% of the mothers were Euro-American; 71% were African American. On average, mothers were 27.3 years of age (*SD* = 7.6) at the time of the infant's birth, and had 13.1 years of education (*SD* = 2.2).

Averaged across the three data collections, mothers rated ease of obtaining help high (*M* = 4.32, *SD* = 0.61). The number of people involved in providing help of various types ranged from 1 to 7 and averaged 3.58 (*SD* = 1.58). Three of the mothers, all in the GP group, reported no source of help with infant care while they were in the home. One GL group mother reported no source of help for care of the infant when she needed to be out of the home.

In the first 4 postterm months, primary care clinic data showed that infants in the GP group had a mean of 3.3 (*SD* = 2.2) visits to the PCC for, on average, 4.6 (*SD* = 4.2) health problems; infants in the GL group had a mean of 2.7 (*SD* = 2.0) visits, on average, 4.3 (*SD* = 3.4) for health problems. Four of the GP infants and one GL infant were hospitalized, three of the five for respiratory problems and two for gastro-esophageal reflux, failure to thrive, and gastrostomy tube placement. Six GP infants and three GL infants had one emergency department visit each during the first 4 postterm months.

Intervention feasibility and usefulness

We examined GP program feasibility in terms of PHN incorporation of GP principles into practice. All four PHNs were able to complete the two visits specified by the GP protocol. For each family on average, PHNs made 5.5 home visits (*SD* = 2.2), 3.3 phone calls (*SD* = 5.7), and spent 5.2 hr (*SD* = 2.4) in face-to-face and phone contact. None of the PHNs or the FSC reported difficulty in using the GP protocols. The PHNs and FSC reported developing patterns of communication suited to the needs of specific families. PHNs reported increased communication with PCCs.

Data concerning the usefulness of the GP program included the feedback of the PHNs and FSC at periodic meetings, a telephone survey of five randomly selected GP group mothers, and evaluation of the guidelines by PHNs, clinic RNs, PCCs, and mothers. Except for minor changes in the protocol for establishing a relationship with mothers during the infant's NICU stay, no substantive changes in the GP program were advised by the PHNs or FSC. Several PHNs reported that the GP program had strengthened their practices with families by making home visits more goal specific and focused on issues of concern to mothers. PHNs used the guidelines to gain mothers' attention and engagement in problem solving and to confidently inform them about illness prevention or needed health problem management. PHNs requested including directions for contacting them, making the guidelines more reader friendly, and adding guidelines for assessing and managing skin problems. Both PHNs and the FSC emphasized the PPC's importance in establishing with families the credibility and usefulness of the guidelines and in providing written infant-specific instructions to help all family caregivers manage health problems.

A telephone interview with each of four clinic RNs indicated that they had not been aware of family participation in the GP program despite the introductory letter and mailed guidelines. In general, the clinic RNs had no contact with PHNs, who were viewed by the clinic RNs as too overworked to accept PC clinic referrals. The clinic RNs had more contact with home health nurses who managed prescribed treatments and assessments after hospital discharge but whose role did not include family development of competency for managing health problems.

The PCC, clinic RN, and PHN ratings of guideline usefulness for specific aspects of family health problem management are shown in Table 1. On average, in contrast to higher PHN ratings, both PCCs and clinic RNs viewed the guidelines as being somewhat to quite helpful. One PCC advised addition of information about appropriate alternative caregivers when the infant was sick and the mother could not care for the child. Several PCCs recommended addition of guidelines for VLBW infant crying, routine baby care, illness prevention, and safety. Two clinic RNs advised earlier introduction of families to the guidelines, earlier circulation of the guidelines into the clinics, and better access of clinic staff to the guidelines before an infant's visit.

The reports of mothers in both the GP and GL groups indicated similar patterns and frequency of use of the guidelines. Although most mothers had read through the guidelines, usually during the infant's NICU stay, three mothers in each group had not used the guidelines at all, primarily because the baby had not been ill. One of the GP group mothers reported that it was easier to call the clinic than it was to first look something up in the guidelines. Two of the mothers in each group had talked with the PCC or clinic RN about the guidelines. Only one mother, in the GL group, reported that the PCC or clinic RN had written instructions for the baby's care in the guidelines. Other than one mother's report that she

TABLE 1. *Clinicians' Evaluation of the Usefulness of the Guidelines for Management of Health Problems*

	Primary-Care Clinician (12)[a]		Clinic Nurse (10)[a]		Public Health Nurse (17)[a]	
Questionnaire Item	*M*	*SD*	*M*	*SD*	*M*	*SD*
How to take care of baby at home	3.5	1.6	3.8	0.9	4.2	0.8
When to contact clinician	3.2	1.5	3.4	1.0	2.2	1.0
How to follow through	3.2	1.5	3.3	0.8	3.6	1.2
What to expect to happen	3.3	1.5	3.8	1.0	4.4	0.6
Who in clinician's office could help	3.2	1.5	3.4	1.0	1.8	0.9

Scale: 1 = *not at all*; 2 = *a little helpful*; 3 = *somewhat helpful*; 4 = *quite helpful*; 5 = *a great deal of help.*

[a] Number of evaluations submitted in response to work with specific families.

TABLE 2. *Assessments of Mothers' Health-Care Resource Use and Maternal Perceptions of Infant Health-Care Quality and the Family-PCC Relationship*

	Guided Participation Group (n = 20)[a]		Guidelines Group (n = 11)[a]	
Variable	*M*	*SD*	*M*	*SD*
Health-care resource use,[b] mothers, 1 month	3.66	0.27	3.69	.38
Health-care resource use,[b] mothers, 4 months	3.61	0.31	3.53	.41
Health-care resource use,[c] clinicians, 4 months	4.58	1.17	5.20	.73
Quality of infant's health care[d]	3.22	0.40	3.17	.86
Family-PCC relationship[e]	2.82	0.45	2.82	.49

[a] Several mothers' data were missing for each variable because of failed data collection.
[b] How I Use Health-Care Resources for My Baby Scale: 1 = *strongly disagree*; 2 = *disagree*; 3 = *agree*; and 4 = *strongly agree*.
[c] Clinician's Assessment of the Mother's Use of Health-Care Resources for her Infant Scale: 1 = *not at all well*; 6 = *very well*.
[d] Your Child's Health Care Scale: 0 = *never*; 1 = *sometimes*; 2 = *often*; 3 = *almost always*; 4 = *always*.
[e] How Things Have Been with My Baby's Doctor Scale: 1 = *strongly disagree*; 2 = *disagree*; 3 = *agree*; 4 = *strongly agree*.
PCC = primary care clinician.

had experienced discrepancies between clinician and guideline recommendations, mothers, on the whole, reported the guidelines as being helpful. Mothers advised a more portable format for taking guidelines to the clinic and inclusion of additional health issues (e.g., teething, sun protection).

Intervention outcomes. Rating scale assessments for each of the three types of outcomes of the intervention that we studied (mothers' competencies in using clinical services and health-care resources, mothers' evaluation of their relationships with the infant's PCC, and mothers' evaluation of the quality of the infant's primary care) are summarized in Table 2. In both groups, mothers rated their competencies in the use of health-care resources high at both the 1- and 4-month assessments. Clinicians' ratings were high as well, but with a larger standard deviation, particularly for the GP group. On average, for both groups, maternal ratings indicated high-quality primary care, but some deficits in the family-PCC relationship. The exact probability test showed no significant difference between GP and GL groups on any of the ratings, clinician or maternal.

Discussion

Overall assessment of the GP intervention

The study, on the whole, supported the feasibility and usefulness of the GP program, suggested development of both the guidelines and protocols for PHN and FSC visits, and indicated directions for future study of GP program outcomes. In particular, the pilot study supports a larger study with a longer and more contingent intervention planned with stronger interdisciplinary collaboration. A larger sample would permit exploration of the effect on outcomes of moderating or mediating conditions, including infant birth-weight and morbidities; maternal education, expectations, and intentions; and family attributes (e.g., poverty, language differences, and minority status) (Seid, Sobo, Gelhard, & Varni, 2004). Exploration of program mechanisms that may have contributed to change in PHN practice, including the guidelines as a reference, the simulated problems, or processes of gaining joint attention and engaging in problem solving with mothers, is needed.

Feasibility and usefulness of the GP program

Clinicians were generally supportive of the guidelines as a source of information for families, although a few did not acknowledge a need for guidelines written specifically for the population of VLBW infants. The accessibility of the guidelines for the small number of VLBW infants likely to be patients of any one primary-care clinic may be most easily managed by mothers who take the guidelines with them to a clinic visit. Reformatting of the guidelines for easy portability is a necessary next step until electronic sharing of information by PCCs and families is widely available.

Although all of the mothers noted the potential or actual usefulness of the guidelines, making full use of them as a vehicle for developing a partnership relationship for health problem management remains an issue. The extent to which the partnership relationship was strengthened for the few mothers who used the guidelines with PCCs or clinic RNs during an infant's acute-care visit is a question we did not study. We intended the GP program to enhance the preventive and health-promotional role of PHNs with the families of VLBW infants and with the NICU nurses and PCCs who worked with the family. The program, however, was not able to overcome systemic challenges to this intention. One of the challenges was the perceived unavailability of PHNs for support of the health of VLBW infants. Communication patterns and expectations for communication between PHNs and NICU nurses and between PHNS and PCCs or clinic RNs concerning VLBW infants are promising but as yet embryonic and even unformulated. The scarcity of both PHN and clinic RN resources may be a major barrier to developing communication patterns. The FSC's contribution to the family's health problem management in partnership with the PCC in the context of assistance with resources, adaptation, and mental health problems and its effect on PHN practice and GP program outcomes needs further study. Strengthening of interdisciplinary and interagency collaboration could help to lay the groundwork for aiding families of premature infants in managing health problems.

Outcomes of the GP program

The lack of significant difference between groups in mothers' competence in the use of clinical services, health-care resources, evaluation of the quality of the infant's primary care, and evaluation of the quality of the family-PCC relationship may be due to inadequate power for detecting difference and instruments that lacked sensitivity to the outcomes we wanted to assess. Many infants were relatively free of health problems, and the GP intervention, structured as it was around simulated situations, may have had limited capacity to engage mothers' attention. GP structured around health problems currently experienced by a family may have a different outcome.

Although mothers had a high evaluation of the quality of their infants' health care, they did not, on the whole, solidly agree that the PCC provided interpersonal conditions needed for collaboration. Questions for further study include social and cultural issues involved in maternal perception of the family-PCC relationship and in family infant health problem management. In-depth study of NICU nurse, PHN, and FSC collaboration for development of the family-PCC relationship and examination of the contribution to infant outcomes of this collaboration is a direction for future intervention research.

Acknowledgments

This study was supported by the Capital Wisconsin Chapter of the March of Dimes, the Aurora Family Service of Milwaukee, Wisconsin Perinatal Foundation, and the National Center for Research Resources, Grant M01 RR03186. Appreciation is expressed to the families who participated in the study; the nursing and neonatologist staffs, nurse administrators (Susan Forbush, Virginia Furomo, Julie Gale, Lisa Jentsch, Patricia Mueller, and Julie Wall) of Milwaukee Level III Neonatal Intensive Care Units (Aurora Sinai Medical Center, Children's Hospital of Wisconsin, St. Joseph's Hospital, and St. Mary's Hospital), and the Milwaukee Health Department who contributed to the study; public health nurses (Polly Belcher, Shirley Cooksey, Wendy Petersen, and Irmine Reitl) who provided the intervention; Aurora Family Service of Milwaukee for support of family service clinician services for the project; Elizabeth Weber for liaison with primary-care clinicians; Michele Schroeder for assistance in training for the project; neonatologists Steven Leuthner, Gregory Miller, Chandra Shivpuri, and John Wolf for medical input and liaison with medical staffs; and Roger Brown for assistance with statistical analysis.

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