

Research - Background & Significance

The Health & Literacy Link

Health literacy is an element of all the Healthy People 2010 Objectives (DHHS 2003b). Further, the Institute of Medicine (2004) reports that efforts to reduce health disparities cannot succeed without improvements in HL. Adverse adult health outcomes are associated with low health literacy (HL), which may lead to over-use of emergency medical services and under-use of preventive services, unnecessary testing and treatment, and increased healthcare costs. However, findings have been inconsistent (Berkman, et al 2004).

Low maternal HL is associated with negative health outcomes for children such as poor development, low immunization rates, low-birth-weight and infant mortality (Robinson & Wharrad 2000; Arya & Devi 1991; Browne & Barrett 1991, Kogan, Alexander, Kotelchuck & Nagey 1994). Preventable low birth weight is one example of how the negative impacts of parents' low HL extend to their children. Kogan et al (1994) reported that in a large nationally representative sample, mothers who recalled learning about specific health behavior topics during pregnancy had a significantly reduced chance of delivering a low-birth-weight child compared to mothers who were not able to access information on those topics. Mothers with inadequate pregnancy health information were more likely to have a low-birth-weight baby despite lower risks. Low birth weight is the leading cause of infant mortality and poor child development.

Examples of how a mothers' FHL may positively or negatively affect child development:

- Her ability to establish a medical and dental home -regular sources of care- for herself and her child
- Her ability to arrange well-child checkups and immunizations
- Her ability to recognize the child's illness and injury, provide appropriate home-care, trigger timely intervention, administer medications and follow treatment regimens
- Her ability to recognize her own depression and access timely treatment

Health Literacy & Functional Health Literacy

This project focuses on mothers' FHL (functional health literacy). It differentiates FHL from HL (health literacy), which is currently conceptualized in the scientific literature as an individual skill – specifically, reading ability in a healthcare setting. In this conceptualization, HL is something you learned in school; you have or you don't. It is unrelated to experience, social support or resources.

In contrast, FHL is “ability to function in the health arena” (Bennett 2003). FHL is a ‘type’ of adult literacy, that is, functional literacy. A person's functional literacy (e.g.

computer literacy, financial literacy, health literacy) changes with the circumstances; it develops over time with need, opportunity and experience. Renkert and Nutbeam (2001) recognize the functional and social aspects of health literacy, in their definition of maternal health literacy as “the cognitive and social skills that determine the motivation and ability of women to gain access to, understand and use information in ways that promote and maintain their health and that of their children.”

No measures of FHL are reported in the literature. Commonly used HL tests measure reading skill and do not assess how the person actually functions in the health arena; they are not measures of FHL (Berkman, DeWalt, Pignone, Sheridan, Lohr, Lux, Sutton, Swinson & Bonito 2004). This project develops and validates scales for measuring levels of functioning in the health care system and in health contexts at home, which will encourage additional research and aid broader of understanding of FHL and how to improve it.

Theoretical Framework

Whether low FHL leads to negative outcomes may depend on the amount of support and resources that individuals receive from their social environment. Lee, Arozullah and Young (2004) suggest that positive supports can improve ability to acquire and understand health and medical information and to negotiate the healthcare system. Conversely, lack of support may amplify adverse health situations for those made vulnerable by low HL. According to the World Health Organization (2000), strategies that increase access to information and build capacity to use it can improve FHL, decision-making, risk perception and lead to informed action by individuals and organizations.

Studies show that HV (home visitation) exerts a positive effect on women’s and children’s health. Kitzman, Olds, Henderson, Hankset, Cole, et al (1997) reported improvements related to home visitation by nurses, including reductions in prenatal cigarette smoking and hypertensive disorders; reductions in children's healthcare encounters for injuries; fewer unintended subsequent pregnancies, improvements in birth spacing and in children's school readiness. Using the LSP, Wollesen (in press) reports significantly reduced depression and violence in families participating in home visitation programs.

These findings are consistent with Lee’s theory of social support and HL and may suggest that social support is a mechanism by which HV buffers impacts of low literacy and increases mothers’ capacity to function in the health arena during pregnancy and early parenting. One purpose of the proposed study is to examine the influence social supports and the visitor-mother relationship on changes in the mother’s HL skill and her ability to function in the health arena.

Specific aspects of social support from home visitation that may affect FHL:

Increasing other social support: HV may enhance the likelihood of accessing and obtaining the benefits of positive support and mitigating negative support from family and friends (Lee et al 2004). Examples of “negative support” include an abusive partner who discourages use of prenatal care or actively injures the mother; and a grandmother who insists that “babies should sleep on their stomachs”, thereby increasing the risk of Sudden Infant Death Syndrome.

Informational support: Aligned with the WHO’s 2000 report, home visitors provide reliable information and assist parents to use information to assess and respond to pregnancy complications, medical conditions, and child health and development problems. The parents’ literacy skills may or may not be altered by informational support. However, such support may have a significant impact on the parent’s functional health literacy, providing a potentially powerful in buffer against the negative impacts of low literacy skills. Useful information also helps reduce uncertainty and anxiety, and provides a personal sense of control over individual literacy problems (such as low HL skills) (Antonucci 2001).

Linking to health resources: HVs (home visitors) offer concrete assistance in selecting and negotiating entry into institutional and community-based health resources, and in obtaining the full benefit of services.

Altering the mothers’ perception of low health literacy: Alonzo and Reynolds (1998) reported that care-seeking behavior is constrained by an individual’s socio-psychological circumstances. The stigma and shame associated with low literacy may prevent many disadvantaged parents from communicating their health needs and obtaining timely appropriate care (Nurss 1998; Parikh, Parker, Nurss, Baker & Williams 1996). Tangible support, such as a HV urging and helping plan a doctor visit, may overcome such limitations (Gotay 1998).

Increasing self-efficacy – the mother’s feeling of confidence that she can do what is being asked of her, and the most significant factor in behavior change (Bandura 1986): The sense of being supported by a HV may enable a parent to face stressful situations that would otherwise seem overwhelming (Holahan, Moose & Bonin 1997; Pearlin & Aneshensel 1996) Although the parent may or may not become more literate, with HV support she may feel less ashamed, more willing to seek help to increase her literacy skills, and more active in seeking advice from the HV and healthcare providers.

Modeling and supporting healthful behavior: HVs may compensate for some of the negative effects of low HL skills and promote FHL by modeling healthy behaviors and supporting parents in making changes.



An Innovative Approach

A few HL studies have controlled for social support (Schillinger, Grumbach, Piette 2002). No studies have investigated whether social support through home visitation moderates the adverse impacts of low HL skills or FHL. Neither has any study examined the role of HL in disparities in MCH outcomes or health services use during pregnancy and early parenting (Berkman et al 2004 p30).

Pregnancy and early parenting present a unique opportunity to promote FHL

Pregnancy is a life transition that triggers independent learning (Orr 1990) and use of significant health services, often for the first time — notably prenatal, obstetric, pediatric and preventive services. Lacey (1988) found that pregnant women and new mothers exhibit readiness to learn well above national norms. Preventable low birth weight is one example of how the negative impacts of parents' low HL extend to their children.

A mother's literacy and FHL affects her child's development.

In poor countries, low maternal literacy level is associated with negative outcomes for children such as poor nutrition, low immunization rates and high infant mortality (Robinson & Wharrad 2000; Arya & Devi 1991; Browne & Barrett 1991). This is attributed to the links between literacy, healthcare utilization and understanding of child care practices (Gross & Auffrey 1989).

The child development literature draws from a wealth of recent research from neurobiology and the behavioral and social sciences. Among the core themes of this literature are that all children are born learning. What happens in the first months and years of life matters because it sets either a sturdy foundation or a fragile foundation for all that follows (National Academy of Science 2000). Supporting and enhancing parents' FHL can be expected to enhance child health and socio-emotional development -- the foundations for early literacy and school readiness (Wilen 2003, Halfon 2004). Thus, by providing social supports to buffer the effects of low literacy skills and promote FHL, MCH home visitation may break multigenerational cycles of low literacy, low FHL, and poor health.

Improving On Reported Health Literacy Studies

Expand Understanding Beyond Reading Skill

Reported HL measures are school-based tests focused on one literacy skill (reading). Commonly used are the REALM (Rapid Estimate of Adult Literacy in Medicine), Wide Range Achievement Test (WRAT) reading subtest, and the Test of FHL in Adults (TOFHLA). The WRAT and REALM are word recognition tests validated as instruments of reading ability. The TOFHLA and a short version (S-TOFHLA) assess literacy by a modified cloze method. All of these instruments measure reading ability. They are highly correlated with one another (Berkman et al 2004). These tests view HL as an individual trait unrelated to social support and resources. They are time consuming for practitioners and lead to anxiety, embarrassment and shame for subjects, who are unlikely to benefit from the testing. Results are reported as school-grade level equivalent, a common but misleading practice since reading ability varies widely within grades (Barton 1994). Since they are one-time tests, they do not allow for progress over time. They cannot measure functioning; only reading ability.

Innovations in measuring and predicting functional health literacy

This project uses the Life Skills Progression instrument (LSP) and the unique access and perspective of HVs to measure and report FHL as a level of functioning on a collection of items that work together to measure the underlying concept of FHL. Repeated measures permit a study of change in FHL over time. Data is immediately useful for intervention planning and so is of direct benefit to the mothers, with no burden on them. Measuring health literacy as progress toward optimal functioning in the health arena can take understanding of HL beyond the current focus on reading skill. This project will explore the ability of the LSP to provide a more useful and meaningful measure of HL, and so make a significant contribution to the field.

This project also uses the ELF Literacy Screen (Bennett 2003) to identify disadvantaged parents at high risk of HL (reading) skill < 6th grade as measured by the REALM. There are several advantages of this innovation:

It allows a conventional measure of HL without the burdens and complications of conventional testing.

It allows comparison of baseline measures of FHL per the LSP with baseline risk of low HL skill per the REALM, providing an indication of the external validity of the LSP to measure FHL.

Repeated measures with both instruments allow comparison of progress through levels of functioning in the health arena with progress out of the high risk category for low HL skill, giving two measures of when (with what service dose) progress occurs.

The screening process facilitates referral to literacy enhancing services, so it promotes HL skill and is of immediate benefit to the mothers.

Health literacy in various settings

Previous HL studies have been limited to clinical settings; however, HL also impacts parents' capacity to function in health contexts at home where they apply health information, engage in health-related behaviors, self-care and infant care; promote child health and development, administer medication and carry out treatment regimens. These functions are not directly visible in the clinical setting.

In addition, healthcare professionals have difficulty identifying patients with low literacy and promoting patients' FHL in a clinical setting due to short infrequent visits (Bennett 2003). In addition, shame over their low literacy may lead patients to conceal their difficulties from providers (Parikh et al 1996). Further, Freebody and Freiberg (1997) discuss the role that expert knowledge and protection of a professional elite play in the opacity of healthcare communication, a process that further amplifies the challenges of HL.

In contrast, HVs maintain close personal relationships with families focused on building strengths through frequent encounters (one to four visits per month) over an extended period (six months to 3.5 years). Given the tools, HVs are positioned to identify disadvantaged parents with low HL skills, provide social supports to buffer adverse effects, and to tailor interventions to promote progress toward higher functioning in the health arena. Also because of their unique access and perspective, HVs are well positioned to directly monitor and record parents' utilization of healthcare services, and their health-related functioning at home, as well as their social support from family and friends.