

Advocacy Oriented Behavior and Health Care Access:

A Conceptual Model of Web-based Health Communication for Children with Juvenile Arthritis

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Abstract

JAHelp, a Web site development project (www.JAHelp.org), funded through a grant from the National Institute on Disability and Rehabilitation Research, postulates that by providing parents, caregivers and others with the information they need to advocate for children's access to health care and other resources, self-efficacy and associated health outcomes would improve. This paper describes a conceptual model that argues that advocacy oriented access behavior can be encouraged through new media and constitutes an important targeted outcome of health care communication.

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The promise of a national health care plan promoted during Bill Clinton's 1992 campaign for the presidency evaporated during the acrid debate that swamped every good intention following his election. In the years that followed, legislators perceived health care reform as a quagmire, and not a single politician attempted to raise the issue in a material way in the 14 years since the Clinton effort floundered.

As a result, health care in United States persists as a conflict-based model, with competing "providers" contending over annual expenditures that grew to nearly \$2 trillion by 2004 (Smith, 2006). Even though Americans outspend any other country in the world (Anderson, 2005), recent data also reveal that they receive little more than half the recommended medical care they need (Asch, 2006). "These results," the authors said, "underscore the profound and systemic nature of the quality-of-care problem." (Asch, 2006, p. 1152)

Figures released this year by the Centers for Disease Control in Atlanta painted a grim picture for children. In 2004, 1.6 million kids failed to receive needed medical care because they couldn't afford it, while another 3 million had to delay trips to the physician because of cost concerns (CDC, 2006).

For children with a chronic illness such as juvenile arthritis (JA), the impact of symptoms, treatment and its side effects, and disability that limits leisure activities and participation at school weighs heavily, generating a psychological and emotional impact that complicates health outcomes. Accordingly, a multitude of factors influence children's attitudes toward their illness, including pain, stiffness, swollen joints, fatigue, sadness, loneliness,

frustration, participation in school activities, participation in sports-related school activities or physical education, participation in family activities, and activities with friends (Barlow, 2001).

The availability of resources plays a significant role. "Parents who perceive they have sufficient resources, both personal and instrumental to effectively manage the concomitants of their children's disease may instill greater arthritis self-efficacy beliefs in their children "(Barlow, 2001, p. 164). That "self-efficacy," a social-cognitive theory pioneered nearly thirty years ago, posits that "people's judgment of their capabilities to organize and execute courses of action required to attain designated types of performance" is associated with improved health status (Brekke, 2001, p. 387; Bandura, 1977).

Children with JA need a constellation of services, including specialist physician care, medications, physical and psychological therapies, and education and self-management skills training (MARRTC, 2004). Access to those services, however, often requires navigating a complex, non-integrated health care system that includes public, private, and school-based programs that are law or regulation laden. The JAHelp Web site development project (www.JAHelp.org), funded through a grant from the National Institute on Disability and Rehabilitation Research and sponsored by the Missouri Arthritis Rehabilitation Research and Treatment Center, hypothesized that by providing parents, caregivers and others with the information they needed to advocate for children's access to health care, self-efficacy and associated health outcomes would improve.

Traditional notions of health communications that involved efforts to raise awareness and encourage behavioral changes that would reduce the likelihood of illness have met with limited degrees of success. In order to create an environment where "people can be healthy" Wallack (2000) urged that media strategies also be aimed at building "social capital," as well. The term is

defined as "an umbrella concept that includes anything that helps to remove the barriers to collective action in communities" (p. 339).

JAHelp, by providing a common vocabulary for parents and caregivers seeking services for children, has the potential to increase community responsiveness to chronic illness. "If ... public health problems are viewed as largely rooted in social inequality resulting from the way we use politics and policy to organize our society, then media matter because they can be a vehicle for increasing participation in civic and political life and social capital to promote social change" (Wallack, 2000, p. 338).

Without an integrated, national health care program or policy, individuals are left to cobble together their own methods for gaining access to medical treatment. Even those who are covered by employer-sponsored health insurance, must contend with co-pays, deductibles and excluded conditions that may raise obstacles to care. In developing the Web site, we hypothesized that improving advocacy skills would enhance self-efficacy and improve consumers' ability to access care programs and laws designed to alleviate the burden of JA.

This paper presents a conceptual model of health communication aimed at enhancing advocacy oriented access behavior, a term we define as activity intended to obtain and then use enabling resources (including knowledge) to more effectively surmount regulatory or legal obstacles to receiving health-related and quality of life-related services. This conceptual model identifies important cognitive and affective antecedents to advocacy oriented access behavior that can be influenced by health communication.

JAHelp places in one location jargon free descriptions of selected governmental programs and laws that can assist children with JA and their families either lessen the impact or better manage the health and associated effects of this illness. The site includes programs that

together can yield the constellation of services children with JA must acquire to develop physically, socially and psychologically to their best potential. JAHelp's core purpose is not, however, to simply describe these programs; it is to assist users in navigating the process by allowing them to determine eligibility, ultimately apply for benefits, and cope with systemic challenges these programs and laws create. (For instance, it's one thing to know about benefits available to children under the Individuals with Disabilities Education Act and Section 504, it's quite another to be able to distinguish the nuanced differences between the two programs and then surmount the application processes they require.)

Many people, of course, face significant barriers when attempting to access health care and related services that are not surmountable despite their best efforts. The term *advocacy oriented access behavior* is not meant to imply that acquiring services is simply a matter of “getting busy at it.” The conceptual model for JAHelp assumes that a significant number of people are unaware of resources or require information that will jumpstart their efforts to obtain them. This conceptual model and the JAHelp project hypothesize that awareness, increased knowledge and enhanced self-efficacy will help some individuals gain enabling resources to access needed services in a more deliberative manner.

Additionally, an accompanying health information dissemination project currently underway will place the Web site not only in the hands of parents and caregivers of children with JA but also with important individuals who interact with them, including pediatric rheumatologists, adult rheumatologists who treat children, pediatricians, social workers and care coordination managers, librarians, school resource specialists, and staff at faith-based institutions. In essence, JAHelp has the potential to be a unifying factor within a community, as stakeholders join in promoting greater utilization of government and private mechanisms for

acquiring care. By linking people toward a common goal, the Web site adds to "social capital," which includes relationships that support advocacy oriented behavior, enhance self-efficacy, and thereby contribute to improving health care outcomes. (This paper does not delve deeply into the social capital element, a topic for future research, but it is important to at least raise the prospect of promoting that type of change.) The actual results of this Web-based effort will be a subject of future study, but the conceptual model we explain here provides a basis for our continuing research.

In practical terms, the JAHelp Web site combines techniques of new media health care communication, self-efficacy enhancement to improve health care access, and elements of conflict/dispute resolution and negotiation skills to support advocacy oriented access behavior. Thus, the conceptual model we propose in this paper contributes to health communication inquiry in two ways. First, it provides a framework within which to examine potential health communication effects on access behavior, including populations with disabling conditions such as JA. Second, it places health communication within a health services use model, facilitating a fresh view of where health communication can intervene to affect people's wellbeing beyond just encouraging healthier lifestyle practices.

Background

Arthritis is an often misunderstood illness. Pervasive among the elderly, nearly two-thirds of people over age 65 have some form of arthritis, an umbrella term that encompasses more than 200 different conditions (MARRTC 2004). The Centers for Disease Control (2006) estimates that 70 million Americans contend with the disease, most of whom are adults. As a result, the debilitating effect arthritis has on children is often underemphasized because of its rarity compared to adult onset. Nevertheless, an estimated 300,000 children nationwide must cope with

the illness' severe symptoms and debilitating impact. In fact, some of them die (MARRTC, 2004).

Juvenile Arthritis and Its Effects

Children with JA experience daily pain, fever and fatigue. As the disease progresses, joint deformities, stunting of growth and death are potential outcomes even when properly treated. Since the disease occurs during a child's formative years, the illness has a profound developmental impact as it interferes with school and family activities, hinders social development, and causes psychological and emotional distress (Arthritis Foundation, 2006a).

Managing care is a full-time job for both parents and children. Treatment plans can include a variety of interventions, including physician visits, surgery, medications, splints or other medical devices, exercise, physical therapy, mental health treatment, education and self-management skills, and nutritional counseling (Arthritis Foundation, 2006b).

Even individuals with comprehensive health insurance plans may have gaps in coverage that exclude some of the required services, or require hefty co-payments and deductibles. For families who have no health insurance coverage, access to care is even more dramatically impeded. Past studies have found a direct link between insurance coverage and access to health care. For instance, uninsured children in fair to poor health were four times less likely to receive necessary medical or surgical care than their insured counterparts (Families USA, 1997). In 2004, 11.2 percent of the nation's children, 8.3 million of them, did not have health insurance. Economic status played a significant role in whether or not a child had any coverage, with 18.9 percent of children in poverty uninsured (DeNavas-Walt, et al., 2005).

The JAHelp Web site proposal hypothesized that children with JA and their families could benefit from a range of public laws, policies, and programs that provide a “safety net” and

facilitate integration of resources that could provide the constellation of services children need. These benefits resources, however, are not user-friendly and/or well-understood by consumers (families) because of the complex regulations, procedures or laws that govern them. During the development of the JAHelp project, we learned from our interviews with disability experts, rheumatologists, care coordinators, parents, and child advocates that parents often expressed frustration at managing not only the care regimen, but finding the resources to pay for them. By providing a user-friendly, educational resource we hoped to transform parents and caregivers into advocates for their children, giving them enhanced ability to access the legal protections, policies, and programs which could enhance coordination of care for children with JA.

We based our proposal, in part, upon a national report commissioned by the Institute of Medicine (IOM) entitled Priority Areas for National Action: Transforming Health Care Quality that identified improvement in “care coordination” as one of the top health care priorities in America (IOM, 2003). It also identified “coordination of care for children with special health care needs” as a particularly important area for national action. The reason for the IOM focus on coordination of care for children with special health care needs is that the research evidence shows that health care outcomes can be significantly improved through the implementation of “coordination of care” programs (Clark, 1984; Young, et al., 2001). The coordination of necessary services for a child with JA is a major challenge for many families; this is particularly the case for families with limited economic resources.

JAHelp

The JAHelp Web site (www.JAHelp.org) provides parents and caregivers information about various public and private benefits programs and laws that provide either medical care,

disability benefits, or educational, employment or lifestyle assistance. It does so by answering the questions most people need to know about potential resources:

1. What is it?
2. What is provided?
3. Am I eligible?
4. What does it cost?
5. How do I apply?
6. What if I am denied?

It provides easy-to-understand answers to these questions for the following programs and laws:

1. Medicaid
2. S-CHIP (State Children's Health Insurance Program)
3. High-Risk Insurance
4. Private Health Coverage
5. Title V Programs
6. Section 504
7. SSI (Supplemental Security Income)
8. ADA (Americans with Disability Act Employment Provisions)

The site is unique in that it provides a one-stop, easy-to-use primer on virtually every way to acquire benefits or resources for the constellation of care a child with arthritis needs. It also does not require significant computer skills to operate. As a result, people with limited abilities should be able to navigate the site easily. People who may assist individuals who have no

computer, or who possess limited computer skills, will be able to easily figure out how the site operates. Assistants could include nurses in physicians' offices, librarians, school resource specialists, staff in faith-based institutions, or even children who may be able to operate the site for their parents.

The site also includes a worksheet that users can generate to accumulate information they will need to actually complete an application. For instance, for those programs that impose financial limitations, the site requests that users accumulate information that can establish eligibility. In the case of educational resources, users are urged to consider how the child's disability affects school performance and to list those effects. If the user consents, the information is stored and assessed as part of ongoing research into utilization of the site. It is not necessary for users to consent to collection of data in order to obtain the full functionality of the site, however. Users receive a personal identification number and submit their information anonymously, thereby warranting complete confidentiality, and compliance with provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Conceptual Model

Andersen's Behavioral Model of Health Services Use offers an integrated explanation of access behavior, originally linking "predisposing characteristics" (demographic, social structure and health beliefs), "enabling resources" (personal/family and community), and "need," (perceived and evaluated) as the underlying factors leading to health care access (Andersen 1995). Anderson (1995) devised this model in the 1960s to explain, as he put it, "the 'how's' and 'why's' of health services' use" (p. 1). Although the unit of analysis was originally the family, he ultimately shifted his model so that it emphasized the individual, since measuring family health status required taking into account too many variables.

Over the next several decades, the model's elements underwent several phases and ultimately fixed on correlating what he termed the "primary determinants of health behavior" (population characteristics, health care system, and external environment), "health behavior" (personal health practices and use of health services) and "health outcomes," (perceived health status, evaluated health status and consumer satisfaction) (Anderson 1995). This model, depicted in Figure 1 and further elaborated in Table 1, remained focused on the use of health services, but it also acknowledged "external environment (including physical, political and economic components) as an important input for understanding use of health services." (Andersen 1995, p.6-7) In the model, environmental factors and population-based characteristics influence health and health care behaviors. Personal health practices and use of health services (along with other factors such as genetics, environmental exposures, and accidental injuries), in turn, determine health outcomes.

The impetus behind the JAHelp Web site's design recognized that in a society that individualizes health care, the ability to find, navigate, and then utilize the various systems devised for providing care could have a significant impact on health outcomes. While Andersen's model acknowledges that personal health practices play an important role, JA onset is not related to anything the child has done. To the contrary, adjustments to behavior are only considered after diagnosis, and must often be carefully monitored through a number of service providers. As a result, "use of health services," becomes a paramount consideration driven by a family's ability to pay for care and services.

Figure 1. The Behavioral Model of Health Services Use and JAHelp (adapted from Andersen, 1995, p. 8).

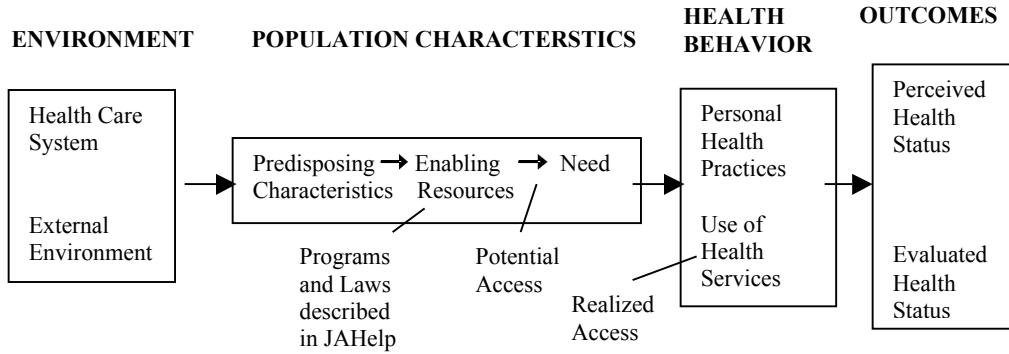


Table 1

Additional Detail in Behavioral Model of Health Services Use

| ENVIRONMENT | | POPULATION CHARACTERISTICS | | | HEALTH BEHAVIOR | | OUTCOMES | |
|-------------------------------------|-----------------------------------|--|--|----------------------------------|---|---|---|---|
| Health Care System | External Environment | Predisposing Characteristics | Enabling Resources | Need | Personal Health Practices | Use of Health Services | Perceived Health Status | Evaluated Health Status |
| Policy Organization Resources | Political Economic Physical | <u>Demographic</u> Age Gender <u>Social Structure</u> Occupation Education Health Beliefs Culture | <u>Personal-Family</u> Health Insurance Income Regular source of health care Knowledge of health care system <u>Community</u> Community providers and services | Evaluated Need Perceived Need | Such as diet, exercise, self-care; includes risk behaviors. | Realized Access to formal, personal health services | As subjectively perceived by individual | As evaluated or diagnosed by physician or other health professional |

Environment

Environmental factors include, at a societal level, policy, organization, and resources of the health care system. Outside of the health care system, external environmental factors include political, economic, physical, and other fundamental realities of the society. The initial behavioral model began with population factors and did not include these environmental factors (Andersen, 1995). Environmental factors were added in later versions in recognition of their importance as indirect determinants of use of health care services.

Population Characteristics

Population characteristics more directly determine use of services. Predisposing characteristics are factors that, at a societal level, are associated with general predispositions to use the health care system in particular ways. They include demographic (e.g., age and gender), social structure, and health beliefs factors. Social structure comprises factors that influence one's familiarity with and ability to navigate the health care system (e.g., occupation and education). Health beliefs influence people's attitude and values toward health and health care and, consequently, influence their perception of need and decisions about use.

The model has been criticized for not including additional influences, such as the affect of culture on health care use (Portes, Kyle, & Eaton, 1992). Culture affects health care use, in part, by helping shape health beliefs. Anderson acknowledges this and suggests that culture would fit conceptually under social structure.

Levels of personal/family enabling resources are associated with predisposing characteristics, especially demographics and occupation. Personal/family enabling resources include means such as health insurance coverage, income, a regular source of health care, and the ability to sustain traveling and waiting times related to any source. The likelihood of a family

having health insurance rises with income (Denavas-Walt, et al., 2005). Families earning more than \$100,000 a year have higher likelihood of being insured, 91.6%, than families earning less than \$25,000, of whom only 75.7% are covered. Partly because Black and Hispanic families have lower median incomes than do Asian or White families (\$30,134 and \$34,241 compared to \$57,475 and \$48,977, respectively), they are more likely to be uninsured. 21.1% of Hispanic children and 13% of Black children are uninsured, compared to 9.4% of Asian children and 7.6% of White children.

Self-efficacy that leads to effectiveness at adding family resources is the fundamental goal of JAHelp and the underlying premise behind assisting parents and caregivers to become better advocates for their children. Community enabling resources include the health care providers and services available in a community. But the existence of providers is only part of the equation, the other being the ability to pay for them. The presence of a pediatric rheumatologist within reasonable driving distance better enables access to specialized care, but only if a family has some means of paying for the service.

Knowledge of the health care system is also a personal or family resource. Enabling resources can be conceptualized as follows: First, community enabling resources of “health personnel and facilities must be available where people live and work. Then, people must have the means and know-how to get to those resources and make use of them” (i.e., they must have an adequate level of personal/family enabling resources) (Anderson, 1995, p. 3).

Access is defined in terms of other factors in the model. Potential access is the presence of adequate enabling resources to use health care services when needed (Andersen, 1995). Realized access is actual use of these services. Realized access is a function of need which, can be either perceived or evaluated – or both. In the case of JA, the perception that is relevant is

most often that of the parent or caregiver responsible for a child's wellbeing. Over time, a child will be indoctrinated into understanding health care needs, as he or she better understands the demands and challenges of chronic illness.

Need is, at least theoretically, the most immediate predictor of health care use. Evaluated needs are health care needs identified or diagnosed by physicians or other health care providers. Perceived health care needs are determined by individuals, and can be influenced by psychosocial factors such as health beliefs (Andersen, 1995).

The theoretical immediacy of need in relation to use can be illustrated by a car accident in which an uninsured passenger is injured, evaluated, and treated at an emergency room, despite lacking the access-enabling resource of health insurance. In chronic health conditions, such as JA, the immediacy between need and use for the uninsured relates to the severity of consequences that can ensue if the health care plan isn't followed. For instance, if pain management protocols are not followed, then the child may experience deterioration in health outcome. Research shows that the uninsured in general wait longer to access the system, often entering through emergency rooms only when symptoms become acute (Families USA, 1997). Uninsured adults have fewer doctor visits annually (Institute of Medicine, 2002) and are 30% more likely than insured adults to skip recommended tests or fail to fill prescriptions (Kaiser Commission, 2000). As a result, the uninsured are 50% more likely to be admitted to hospitals for “avoidable conditions” such as pneumonia or uncontrolled diabetes (Institute of Medicine, 2001). A study by the Institute of Medicine (2001) found that the uninsured were 25% more likely to die than those with private health insurance. In the case of JA, permitting chronic symptoms to become acute can have dire consequences.

Health Behavior

Use of health services (Andersen, 1995) is categorized as a health behavior in the model. It refers to the use of formal personal health services such as physician or hospital services. The term is synonymous with realized access. The other health behavior included is personal health practices (Andersen, 1995). These include, for example, diet, exercise, self care, and risk behaviors such as smoking and unsafe sexual practices. Personal health practices have been a dominant focus of health communication. Andersen's model facilitates a broader view of health behavior, one that includes use of health services, which in turn, along with personal health practices, influences health outcomes.

Outcomes

Perceived health status at the individual level is one's subjective perception of his or her health. Evaluated health status is determined by health care professionals, similarly to evaluated need (Andersen, 1995).

Mutability

The concept of mutability is important in this model since the ability to alter the impact of individual factors helps answer a significant question: What can be most efficiently or plausibly changed in order to achieve desired health outcomes? When he initially considered mutability in his model, Andersen (1995) determined that demographic and social structure factors were mostly impervious to change, while health beliefs were of "medium" malleability. Variables such as gender and ethnicity cannot be changed and variables such as occupation and education evolve slowly. Health beliefs, on the other hand, can be altered more quickly than other social structure variables and can, in turn, affect health and health care behavior.

Andersen (1995) judges the mutability of enabling factors to be “high.” Within a health policy framework, Andersen (1995) describes need as “originally considered not to be a mutable policy variable but rather the immediate reason for use to take place. However, people’s perceived need for care may be increased or decreased through health education programs, changing their financial incentives to seek services, and so on” (p. 5). In the articles reviewed, Andersen did not venture an initial hypothesis about the mutability of personal health practices. The literature of health communication, however, shows campaigns aimed at personal health practices, overall, have had moderate effects at best on behaviors such as cigarette smoking, alcohol consumption, diet, and unsafe sexual practice , with some campaigns having behavioral effects that were “notably weak” (Atkins and Marshall, p. 490). Mutability is an important dimension in health communication because it helps aim or focus interventions at variables that may have greater likelihood or, at least, potential to change. From the JAHelp perspective, transforming concerned parents and caregivers into advocates depends on mutability and whether these individuals will respond to incentives offered by the benefits programs and laws. This transformation could then translate into assertive behaviors geared toward clearing bureaucratic obstacles.

Advocacy Oriented Access Behavior

Realized access or use of services on a regular basis can help individuals better manage a chronic condition. In addition, beginning treatment sooner minimizes physical suffering, reduces pain, and often avoids the aggravation of symptoms or the severity of illness. We propose that advocacy oriented access behavior benefits children with JA, because it enhances enabling resources to a level that allows for realized access that promotes prevention, detection, and expediency in treatment of medical problems. Concomitantly, health communication is

appropriately focused on advocacy oriented access behaviors to encourage utilization of programs and laws that enable early health services acquisition. In the language of this model, advocacy oriented access behavior seeks potential access with which to effectively manage realized access.

Equity

At a health policy level, the model has been used to measure and prescribe changes that promote equity in access to health services, based on ideals such as social justice (Aday & Andersen, 1981). Andersen (1995) defines equity of access in terms of other variables in the model. He defines equitable access “as occurring when demographic [e.g., age and gender] and need variables account for most of the variance in utilization” and inequitable access as occurring “when social structure variables (e.g., ethnicity), health beliefs, and enabling resources (e.g., income) determine who gets medical care” (p. 4). In short, Andersen argues that medical care should be allocated based on actual, evaluated medical need, also considering demographic variables that affect medical need, such as age and gender. Access allocation based on social or psychological variables, such as social structure, health beliefs, and enabling resources, instead of biologically-based need, leads to inequitable use. For this reason, Andersen categorizes ethnicity within social structure and not as a demographic variable in his model.

Selected Antecedents to Advocacy Oriented Access Behavior

This conceptual model identifies three key antecedents to advocacy oriented access behavior as defined: awareness, knowledge, and self-efficacy (see Figure 2.) Juvenile arthritis caregivers must first be aware that the resources described in JAHelp exist. Individuals must then have sufficient knowledge to determine their potential eligibility for benefits, the services provided or covered, and the like. Applicants also must then have sufficient knowledge to

navigate and complete the application process. JAHelp, by including all available programs in one place and providing a vocabulary for advocacy by generating familiarity with available resources, promotes these antecedent behaviors. Once eligible, users must know enough about the health care system to effectively use the program and its services.

Thus, self-efficacy plays a vital component, since individuals not only need to pursue enabling resources but then actually use the health care system. Albert Bandura's (1977) concept of self-efficacy concerns a person's confidence in their ability to perform certain actions in specific situations. A goal of JAHelp is to increase perceived self-efficacy, which should help bolster determination and persistence in navigating bureaucratic application processes and complicated health care choices.

Figure 2. Antecedents to Use of Health Services or Access.

Awareness ⇒ Knowledge ⇒ Self-Efficacy ⇒ Advocacy-Oriented Behavior ⇒ Enabling Resources ⇒ Access

JAHelp Within the Model

Figure 1, earlier, locates JAHelp's focus on advocacy oriented access behavior in learning about, applying for, and using existing governmental programs and laws to access needed health services. Increasing enabling resources represented by these programs and laws, including knowledge about how to use them, provides a level of potential access. Need triggers actual use or realized access. Evaluated need is already established for children diagnosed with juvenile arthritis.

The already established link between regular and timely access to health care services and better evaluated health status is fundamental to the argument of targeting advocacy-based access behaviors in health communication. Resources that enable potential access moderate the

frequency and timing of realized access and, in this way, affect evaluated health status (and undoubtedly perceived health status).

Mutability is also central to this strategy. Behaviors related to learning about and applying for available assistance and protections is assumed to be more mutable than personal health practices. This difference in mutability or changeability of necessary behaviors has not been tested, but if found, a strategy aimed at access behavior could represent a quicker and more direct route to improvements in health status for potentially eligible people than a strategy aimed at personal health practices. The degree of mutability may be a productive focus of future study.

Although the goal of JAHelp is advocacy oriented access behavior and not equity per se, a few comments on this construct are in order. Qualifying criteria for programs and laws under JAHelp are based on either income or physical needs. For programs or laws based on physical needs, some children will qualify for help because of their particular JA symptoms. For financially based help, some children will qualify because they are in lower income families. Access (leading to utilization) based on need is consistent with Andersen's definition of equitable access. Access based on insufficient income moves toward addressing the inequity that Andersen defines when access is only for those with enough money. JAHelp at least moves toward equity in access as defined by Andersen.

JAHelp targets the three hypothesized antecedents to proactive access behavior. The Web site makes users aware of programs and laws that potentially can help them. It is assumed that many users will not have been aware of the full range of programs described. Awareness is necessary to even apply for benefits or protections. Knowledge of each program and law is provided, including what benefits or protections are afforded, who is eligible, and how to apply.

In some instances, how to more effectively use services or protections is also provided. This would be useful for applicants who qualify, when they begin using services or protections.

By increasing understanding of these programs and enhancing skills knowledge, JAHelp improves perceived self-efficacy in applying for benefits or protections under them. The adage “knowledge is power” applies. In addition to straightforward descriptions, content includes resources to contact for help in determining eligibility and in applying. Furthermore, a section addressing “What if I am Denied?” is included for each program and law, empowering users to know what to do and who to contact if they believe they have been wrongfully or unfairly denied benefits or protections. Through knowledge and identifying help and support, content of the Web site aims to increase perceived self-efficacy necessary to navigate and resolve disputes in applying for, and even using, these programs and laws. In a health care system that is largely individualistic and that often excludes individuals for a variety of reasons, placing parents and caregivers in the advocacy role aims at enhancing awareness, knowledge, and self-efficacy defined by the model.

Parents as Advocates

At this stage, defining in practical terms the concept of parents as advocates outside the model's framework can help visualize the role the Web site encourages. Parents and caregivers of children with JA face the long-term challenges of a chronic illness that left untreated can impose dire consequences. We argue that those parents and caregivers who become more skillful at navigating a health care system with resources that are not integrated will achieve greater success than those who do not.

The available resources are nestled within various sectors, either government or private health care payers, government or private disability benefits providers, educational resources,

and general laws that protect disabled individuals. Without a centralized national health care policy, individuals with the ability to manage access to varied and non-centrally located resources should gain greater access to the constellation of services required by children with JA.

Health Communication Within a Health Services Use Model

Table 1, earlier, provides sufficient detail of Andersen's (1995) Behavioral Model to identify examples of where health communication fits within a health services use framework.

At a societal level, opportunities exist for health communication in examining political communication and discourse on health policy. Political communication during the Clinton health reform effort, including media coverage and associated public opinion, provides a good example. Burgeoning health care costs, a growing proportion of elderly, and the substantial portion of Americans without health insurance, along with vested business interests not easily modified, are among the factors that turned health reform into an insoluble issue. As a result, how individuals obtain access to health services is inconsistent through geographic, demographic, social and socio-economic levels. This variability affects the levels and organization of resources available to individuals.

Rather than generating an approach that provides universal access to quality care at an affordable price, the United States relies instead on a largely individualistic approach with a substantial emphasis on employer or government supplied health plans. But even these programs contain gaps that must largely be filled by collecting resources from diverse sources. JAHelp isolates these varied sources into one place, and permits parents and caregivers to raise their awareness and knowledge as a route to enhancing self-efficacy. We hypothesize that greater task specific self-efficacy will encourage advocacy oriented access behavior that will lead to better health care and associated improved health outcomes for children with JA. In future studies, we

will be able to gauge whether the model and its anticipated goals can actually be achieved using a Web-based intervention.

JAHelp is an example of health communication aimed at influencing enabling resources through targeted behaviors. The enabling resource of broad knowledge of the health care system can be viewed as health care literacy. Whereas its counterpart, health literacy, is concerned with background knowledge necessary to effectively understand and use information about physical health, health care literacy would include the same concerns about the health care system.

Perceived need can be approached from more than one perspective. Based at least in part on health beliefs, African-American women in Frisby's (2002) study perceived the need for mammograms differently than did other women. Perceived need can be influenced by advertising. An interesting area of research is the growing demand for elective cosmetic surgery. What are the relative influences of direct advertising of these services as compared to the popular media's exaltation of youth, attractiveness, and thinness?

Behaviors related to personal health practices are a dominant dependent variable in health communication. This health service use model also highlights use of health services as an important variable. JAHelp is not only interested in potential access, but also in realized access or use that is regular and timely so that health problems, if not preventable, can be at least be detected and treated at an early stage.

Some may argue that health care system structure, process, and use are not health communication variables: that health communication is solely about physical health and associated behaviors and processes such as personal health practices or physician-patient interaction about symptoms, treatment, and so on. This paper argues that communication about

health care system variables, such as access, is ultimately important to physical health and avoiding illness.

Brashers and Babrow (1996) observe that “no other human phenomenon is more elemental than health and illness, none connects us more viscerally with our aspirations, or confronts us more palpably with our limitations” (p. 243). This paper argues that, because it ultimately affects people’s experiences of health and illness, communication about laws and benefit systems is no different than other issues relating to health. Health communication targeted at advocacy oriented access behavior is consistent with future directions for the field as identified by Guttman (2003): “As it is increasingly evident that health is linked to socioeconomic inequities, health communicators may feel their obligations entail a commitment to reduce social and economic disparities” (p. 668).

Summary and Implications

This paper examined health communication within a health services use model. In response to a Web site project aimed at helping children with juvenile arthritis and their families, a conceptual model of health communication aimed at promoting access behaviors was evaluated as a means of better understanding the rationale behind the JAHelp's design and purpose. Additionally, health communication is broadly examined within a health services use model, thus expanding its potential target variables beyond personal health practices. Advocacy oriented access behavior is identified as a possibly fruitful target because of its potentially high mutability and the established link between access enabling resources and health outcomes. Whether encouraging such behavior will have the intended effect will be a rich area for further study.

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