



HEALTH LITERACY ISSUES IN INDIVIDUALS WITH PHYSICAL DISABILITIES

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IMPACT OF LITERACY ON HEALTH

Literacy affects

- health knowledge,
- health status
- access to and appropriate use of health services.

Library of Medicine, 2004

HEALTH LITERACY

The degree to which individuals can *obtain, process, and understand* the basic health information and services they need to make appropriate *decisions* about one's own health (in the context of physical disability).

Health literacy commonly affected in those with physical disability: Their ability to

- Obtain health information (not known or never studied, not readily accessible, or not shared because of paternalistic attitudes and bias of clinicians and society)
- Process health information (if not made relevant or considered by others to be important to persons with disability)

Health literacy commonly affected in those with physical disability: Their ability to

- Understand health information (if not provided or made pertinent to the needs of person with physical disability).

Consequences of inability to access, process and/or understand health-related information



- Lack of access to needed care and health-related services, *and*
- Inability to make informed decisions about own care

EFFECTS OF INABILITY TO MAKE INFORMED DECISIONS ABOUT OWN HEALTH CARE

Bias of others and own low level of health literacy



Decisions are made **for** and not **by** or **with** persons with physical disability



May lead to increased dependence and passive acceptance of others' decisions

ISSUES RELATED TO AVAILABILITY OF INFORMATION:

In those with physical disabilities from childhood or adolescence



Isolation or barriers to health-related education as children/adolescents



Low level of health literacy as adults

Issues related to processing and understanding of information:

SOME PHYSICAL DISABILITIES (E.G., MS, CEREBRAL PALSY, STROKE) MAY HAVE A COMPONENT OF COGNITIVE IMPAIRMENT



Low level of health literacy

Issues related to lack of information on topics relevant to people with physical disabilities:

INADEQUATE KNOWLEDGE ABOUT EVEN COMMON HEALTH ISSUES



LACK OF HEALTH PROMOTION ACTIVITIES (PREVENTIVE HEALTH SCREENING AND STRATEGIES TO REDUCE RISK)



INCREASED INCIDENCE OF PREVENTABLE SECONDARY HEALTH CONDITIONS

SPECIFIC EXAMPLE OF LIMITED ACCESS TO NEEDED INFORMATION BY WOMEN WITH DISABILITIES DURING PREGNANCY

- Bias on part of clinicians who believe they know best what is needed by women with disabilities
- Beliefs of clinicians that they know what is best for women related to childbearing decisions
- Clinicians don't ask, don't explain, don't answer questions, and don't share information with women with disabilities.

CONSEQUENCES OF LIMITED ACCESS TO INFORMATION OF WOMEN WITH DISABILITIES DURING PREGNANCY

- Fear of the unknown (effect of disability on pregnancy and of pregnancy on disability).
- Lack of preparation for labor and delivery, postpartum period, and childcare.
- Have to be innovative/self advocates in the absence of important information that all individuals with disabilities want, need and deserve.

WHAT CAN WE DO TO IMPROVE THE SITUATION FOR INDIVIDUALS WITH PHYSICAL DISABILITIES?

- Ensure that persons with disabilities are included in health literacy research
- Query individuals with physical disabilities about their unmet needs related to health and health care
 - (They know better than anyone else and need to inform decisions made so that they are key to decisions and not merely on the receiving end of others' decisions)
- Ensure that the views of persons with physical disabilities are heard; their views must be primary in decisions made about their health and health care.

