



# **Literature Review & Analysis**

# **For More Information**

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# CHEDI: Consumer Health Education Institute University of Virginia Health System

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# **Executive Summary**

# **Overview of CHEDI and TEACH**

The Consumer Health Education Institute (CHEDI) is an interdisciplinary research and development organization dedicated to the health of all individuals through the use of information and education. It is our belief that through the utilization of innovative, consumer-centric methods for the provision and exchange of targeted health information, we can facilitate the provision of high quality health care for all Virginians and serve as a model for the rest of the country.

Our flagship project, Tailored Educational Approaches for Consumer Health (TEACH), focuses on the use of market segmentation to differentiate information consumers into distinct groups based on specific characteristics and preferences that impact the optimal delivery of health education materials. This novel approach is being explored using data on a statewide sample of Virginia adults, and tested in small subsets of patients who receive their care at the University of Virginia.

# **The Literature Review Process**

One of the important first steps in TEACH was the identification of relevant variables to include in our market segmentation model. We used a comprehensive approach and the combined skills and expertise of a multidisciplinary group along with a formal review of the academic literature. Our Literature Review Team (LRT) includes experts in education, instructional technology, health care and medicine, neuropsychology, medical informatics, and program evaluation, and brings together faculty members from the Curry School of Education, the Department of Public Health Sciences, and the Department of Psychiatric Medicine.

We began with a brainstorming activity to develop a list of potential variables to include in our model. Any construct that would potentially impact the effects of health information or patient education was identified. This was followed by a detailed literature review to gather and evaluate evidence related to these variables. For example, our initial list included variables such as literacy level, learning style, and locus of control. The subsequent literature review attempted to understand the extent to which these variables directly impacted the successful delivery of health information. Some variables, such as basic demographic information, were not included in the literature review, as this information is clearly needed to adequately describe our market segments. A detailed description of our methods is included later in this document. The team identified a broad range of variables for consideration. Variables were categorized and distributed to members of the LRT on the basis of their skills and expertise. Each member completed a comprehensive review of the available literature and developed a summary of their findings (included at the end of this report).

#### **Summary of Findings**

As the team reviewed the literature, it became clear that there were different types of evidence available about the variables. *Causal* evidence is based on methodologically rigorous research that demonstrates that adapting a given educational intervention or set of materials on the basis of a given variable directly leads to increased knowledge, positive behavior change, and/or positive health outcomes. Correlational evidence is evidence suggesting that a particular variable correlates with either information-seeking behavior or health status. While there were other factors that we considered in our decision to include a particular variable in our segmentation model, larger weight was given to the availability and level of evidence identified for each variable.

The majority of variables lacked strong causal evidence, primarily due to lack of original research that sufficiently relates to health status or information-seeking behavior. This supports our contention

that our TEACH initiative is both novel and important in terms of filling current gaps in the state of the science of health education. More commonly, variables were associated with correlational evidence, suggesting that they play an important role in the process of health education. Our methods and findings, reported in this document, should be of interest to a broad audience of organizations and individuals who develop and/or deliver health education materials and interventions to patients and consumers.

# A Closer Look at the Variables

# The Visual Depiction of Factors Related to Health Information-Seeking

To facilitate an understanding of the ways the variables we identified potentially influence health communication, we created a visual model that includes the factors we identified (Fig. 1).



**Figure 1: Visual Depiction** 

# Summarizing the Evidence

As the team reviewed the literature, it became clear that there were different types of evidence available about the variables. The strongest type of evidence is causal evidence. This is methodologically-sound research that demonstrates that adapting a given educational intervention or set of materials on the basis of a given material directly led to increased knowledge, positive behavior change, and/or positive health outcomes. *Correlational Evidence* refers to evidence that a particular variable correlates with either 1) information-seeking behavior or 2) health status or health behaviors. We considered other factors in the decision variables to include in our segmentation model, large weight was given to the availability and level of evidence identified for each variable.

		Evidence <sup>1</sup>		
		Causal	Correl	ational
Variable	Operational Definition	Adapting Health Info on Variable Leads to Health Knowledge +/or Behavior	Information Seeking Behavior	Health Status or Behavior
Personal and Fa	amily Health			
Personal Health Status	Refers to a consumer's perceived healthiness, which may be drastically altered by a new diagnosis or stage of illness (e.g., newly diagnosed, acute illness, or chronic illness)	$\bigcirc$	$\bigcirc$	
Perception of Health Risks	The estimated perceived likelihood of getting a specific disease within the consumer's lifetime. The perceived risk is often influenced by the family's health history.		•	$\bigcirc$
Health Behaviors	These include activities that have a direct impact on the health and wellness of individuals, including dietary habits, activity / exercise levels, and use of alcohol, tobacco or illegal drugs.	$\bigcirc$	$\bigcirc$	
Social Support	"The positive, potentially health-promoting or stress buffering aspects of relationships such as instrumental aid, emotional caring or concern, and information" (House, Umberson, & Landis, 1988).			•

#### Table 1: Levels of Evidence for Each Variable

<sup>1</sup> In the above table, the strength of evidence found in the research literature is denoted by:

= Level 3: Significant support found for the variable and the outcomes or correlates of interest

= Level 2: Moderate support found for that variable and the outcomes or correlates of interest

 $\bigcirc$ 

= Level 1: Limited or no support found for that variable and the outcomes or correlates of interest

Personality Traits				
Self Efficacy	TEACH uses Perceived Health Competence (PHC; (Smith, Wallston, & Smith, 1995)), a generalized but health-related form of self efficacy. PHC is self-efficacy for managing own health outcomes.	2	0	
			Evidence	
	1	Causal	Corre	lational
Variable	Operational Definition	Adapting Health Info on Variable Leads to Health Knowledge +/or Behavior	Info Seeking Behavior	Health Status or Behavior
Personality Tra	its continued			
Locus of Control	The degree to which an individual expects that valued health outcomes are influenced by his/her own behavior (internal control) or by external factors beyond one's control, such as "powerful others" or chance (external control) (Wallston, Wallston, & DeVellis, 1978).		0	
Decision- Making Preference	The type of role an individual prefers to have in health care, ranging from primary active decision maker, through a collaborative role in which decisions are made with a care provider, to a passive role in which a care provider is the primary active decision maker.	0		
Cognitive Fact	tors			
Cognitive Ability	Cognitive ability includes general intellectual ability, learning, verbal and visual memory, the ability to process information rapidly, attention skills, and the ability to meaningfully organize information.			
Reading Literacy	"Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential (Kirsch, 1993).			
Learning Styles <sup>3</sup>	The method by which individuals process and learn information most effectively.	$\bigcirc$	$\bigcirc$	$\bigcirc$
Health Literacy	The "degree to which individuals can obtain, process and understand the basic health information and services they need to make appropriate health decisions"(Ratzan &		$\bigcirc$	

 $<sup>^2</sup>$  Across many studies using a more behavior-specific form of self-efficacy than Perceived Health Competence, in which self-efficacy for different specific health behaviors is measured.

<sup>&</sup>lt;sup>3</sup> Despite the lack of relevant data in the research literature, this factor was included because professional consensus determined that this was an important area for future research

	Parker, 2000)		
Numeracy	Quantitative literacy, the ability to handle basic probability, mathematical and numerical concepts.	$\bigcirc$	

		Evidence		
		Causal	Corre	lational
Variable	Operational Definition	Adapting Health Info on Variable Leads to Health Knowledge +/or Behavior	Info Seeking Behavior	Health Status or Behavior
Personal Healt	th Care Coverage			
Type of plan: individual or family plan	Health plan choices differ depending on whether the consumer has an individual or family plan. (e.g. a young person with a family plan behaves more like an older person with a family plan than a young person with an individual plan).	0		
Health System Engagement/ Utilization	Refers to the level of engagement with the health system and utilization of various medical services, including emergency room use, outpatient visits, inpatient hospitalization, and insurance status (insured vs. uninsured).			0
Satisfaction with plan and physician.	Satisfaction with plan and with physician are factors in choice of another plan.	0		
Plan Tenure	Health plan choice is impacted by the length of time in a plan or with current employer. "Status quo effect"	$\bigcirc$		
Risk Aversion	Risk aversion is the degree to which one chooses the less risky alternative. Related to the factors that cause over-insuring, including one's value of health care and the need to have protection against financial loss.	0	$\bigcirc$	

Information & Information Seeking Preferences				
Information Seeking Behaviors	The communication channels that an individual has used in the past, satisfaction with those channels, and satisfaction with the information obtained.			$\bigcirc$
Information Seeking Preferences	The communication channels that an individual prefers to use; the amount and type of information desired.	$\bigcirc$		$\bigcirc$

# Methods

# **Identification of Potential Variables**

An initial brainstorming session was conducted to identify patient characteristics and preferences potentially related to health information seeking and health behavior for potential inclusion in the market segmentation survey. These variables were then grouped into clusters of variables and assigned to members of the literature review group (Appendix A) for investigation. It is important to note that not all variables identified were included in the literature review. Since the main purpose of this process was to assist in the decision-making process regarding which variables to include in our survey instrument, the literature review did not include variables such as demographics, which had already been determined to be necessary to describe the segments our analysis would help create.

#### **Literature Review of Potential Variables**

The literature review group identified appropriate search engines and developed an abstract form for summarizing articles. These are summarized below:

#### Search strategies

Multiple search strategies were utilized, including search engines and identification of references from secondary sources. Search engines used included Medline, Educational Resources Information Center (ERIC), Cumulative Index to Nursing & Allied Health Literature (CINAHL), Health and Psychosocial Instruments (HAPI), PsycINFO, ISI Web of Science, and Google.

#### Abstracting forms

The literature review group developed a form for abstracting articles with the goal of standardizing the process across reviewers. Articles identified through search engines were obtained and summarized using the following outline: Date of review

Characteristic/preference Outcomes Type of information Items/scales Study design Project related findings Valuable background information/theoretical framework Quality of article/research Sticky issues/Critical discussion/Sensitive issues New search terms identified

A sample completed abstracting form is shown in Appendix B.

#### Literature review summaries

Each member of the literature review group then synthesized the available information on assigned variables and produced a succinct summary of the literature using the following outline: Definition Relative importance to project Research supporting effectiveness Measurement issues (ease, reliability, validity) Stability/use of variable across different situations Other

The summaries for all variables investigated in the TEACH project are available in Appendix C.

# Appendix A: Literature Review Group

#### Overview

The Literature Review Group for TEACH includes experts in instructional technology, evaluation, clinical informatics, neuropsychology, and health services research, combining faculty throughout the University of Virginia. This group is supported by the larger TEACH team listed below.

### **Literature Review Group**

- Wendy Cohn, PhD, Assistant Professor in the Department of Public Health Sciences in the University of Virginia School of Medicine, is the project director for the TEACH project. With the other team members, she developed the process for selecting the variables for inclusion. She was responsible for the review of health literacy.
- Jason Lyman, MD, MS, Assistant Professor in the Department of Public Health Sciences in the University Of Virginia School of Medicine, is a physician with expertise in pediatrics and clinical informatics. He participated in the development of the process of literature review and was responsible for review of health behaviors.
- Donna Broshek, PhD, Assistant Professor in the Department of Psychiatric Medicine in the University of Virginia School of Medicine, participated in the development of the literature review process and was responsible for several variables including health status, learning style, and cognitive abilities.
- Mable Kinzie, PhD, Associate Professor of Instructional Technology in the University of Virginia Curry School of Education, participated in the development of the literature review process and was responsible for several variables including self-efficacy, locus of control, and decisionmaking preferences.
- Jane Schubart, PhD, MS, MBA, Assistant Professor in the Department of Public Health Sciences in the University of Virginia School of Medicine, participated in the development of the literature review process and was responsible for several variables including information-seeking preferences.
- Aaron Pannone, MS, Research Assistant in the Department of Public Health Sciences in the University of Virginia School of Medicine, collaborated on several variables including numeracy, and the variables related to health plan choice.

Assistance provided by:

Sandra Pelletier, PhD, Assistant Professor in the Department of Public Health Sciences in the University of Virginia School of Medicine, collaborated on the variables related to health plan choice.

#### **Other TEACH Members**

- Arthur Garson, Jr., MD, MPH, Dean of the University of Virginia School of Medicine and Vice President, James Carroll Flippin Professor in Medical Science, is a senior advisor on the project.
- William Knaus, MD, Evelyn Troup Hobson Professor and Chair, Department of Health Evaluation Sciences in the University of Virginia School of Medicine is a senior advisor on the project.

- Mick, David, PhD, MHA, Robert Hill Carter Professor in Marketing in the School of Commerce, is a member of the Market Segmentation Group.
- Guterbock, Tom, PhD, Director, Center for Survey Research, University of Virginia, is a member of the Market Segmentation Group.
- Hartman, Dave, PhD, Research Scientist, Center for Survey Research, University of Virginia, is a member of the Market Segmentation Group.
- Conaway, Mark, PhD, Director, Division of Biostatistics Department of Health Evaluation Sciences in the University of Virginia School of Medicine, is a member of the Market Segmentation Group.

# Appendix B: Sample Abstracting Form

**Ref:** Yarcheski et al. (2004). A meta-analysis of predictors of positive health practices. <u>Journal of Nursing</u> <u>Scholarship</u>, <u>36</u>, 102-108.

Date of Review: 2/23/05

Characteristic/Preference: health status/health behavior

**Outcomes:** Positive health practices. Participation in health promotion activities (e.g., exercise, relaxation). Operationally defined in the Personal Lifestyle Questionnaire (PLQ).

Type of information: Measurement/meta-analysis.

**Items/Scales:** Personal Lifestyle Questionnaire – 24 items on 4-point scale (PLQ; Brown, Muhlenkamp, Fox, & Osborn, 1983).

**Study Design:** 37 studies were identified that used the PLQ to measure positive health practices. Fourteen predictors of positive health practices were identified from these studies. A meta-analysis was conducted to reveal the strength of the relationship between the individual predictors and positive health practices.

# **Project related findings:**

- Eight predictors had moderate effect sizes: loneliness, social support, perceived health status, self-efficacy, future time perspective, self-esteem, hope, & depression.
- Six predictors had small effect sizes: stress, education, marital status, age, income, & sex.
- Demographic variables had the least effect on positive health practices, esp. sex & income.
- Loneliness was the strongest predictor and approached a large effect size.
- Four predictors did not meet the criteria of "fail-safe N's below the reasonable tolerance level": income, marital status, depression, stress

Valuable background info/theoretical framework: PLQ

**Quality of article/research:** The systematic searching and identification of appropriate studies, meta-analysis, and statistical standards appear quite good.

# Appendix C: Individual Variable Reports

### Variable: Health Status

#### Definition

Refers to a consumer's perceived healthiness, which may be drastically altered by a new diagnosis or stage of illness (e.g., newly diagnosed, acute illness, or chronic illness) as well as family health status.

#### Bottom Line

Moderate. A correlational study revealed that health status was a moderating variable between critical thinking and 1) health promotion behaviors (e.g., diet, exercise) and 2) secondary prevention behaviors (e.g., early disease screening), but not between critical thinking and health protection behaviors (e.g., prevention of injury such as seatbelt use or immunizations) (Settersten, 2004). A meta-analysis identified predictors of positive health practices and eight predictors had moderate effect sizes: loneliness, social support, perceived health status, self-efficacy, future time perspective, self-esteem, hope, and depression (Yarcheski, 2004). Demographic variables had the least effect on positive health practices.

With chronic health conditions, learning about the disease occurs over a number of years (Monsivais, 2003). This raises the issue that patients may need to be re-educated as new research developments arise pertaining to their health condition and that part of education may be correcting misperceptions and updating outdated information. There is also a great deal of overlap with the Prochaska stages of change model. However, a review of research indicated that the stages specified in the Prochaska model were not consistent across health problems (Rosen, 2000).

In regard to health plan choice, the average consumer is quite sensitive to price (price elasticity) (Strombom, Buchmueller, & Feldstein, 2002) and for those with good health status cost is the most important factor in their decision (Fowles, Kind, Braun, & Bertko, 2004; Strombom et al., 2002). Using open enrollment data with health status from hospital discharges and cancer registry data for self and family, Strombom, Buchmueller, and Feldstein found that younger, healthier consumers were 2 to 4 times more cost sensitive than older consumers with poorer health status. With regard to other health plan information such as performance data, Lubalin et al, 1999, found that consumers seek information specifically about the services and benefits they use (Lubalin & Harris-Kojetin, 1999). Network information preference related to health status is evidenced by [Gates, et al 2004], where younger, healthier consumers cared more about physician network while those older and less healthy cared more about specialist networks. Furthermore, in an unpublished RAND study by Buntin 2000 as cited in (Atherly, Dowd, & Feldman, 2004), healthier beneficiaries were attracted to plans with lower primary care co-pay and larger primary care physician networks and sicker beneficiaries on specialty co-pays and networks and higher perceived quality.

Modeling of health plan choice as it related to health status demonstrated that younger and healthier (self rated) were more likely to enroll in M+C (Medicare plus choice) (Atherly et al., 2004). Those with a chronic disease were more likely to enroll in M+C as well. Modeling showed that the most important plan characteristic is the drug benefit, which increases the probability of enrolling significantly (vision and mental health benefits are much less important). "High–cost beneficiaries" are attracted to drug and vision benefits as evidenced by the following: the number of chronic diseases and drug benefits. Lower cost beneficiaries were more likely to join plans including dental benefits (Feldman, Dowd, & Wrobel, 2003).

Poor health status and greater utilization of health services in the previous year have been related to the decision to switch health plans (Oetjen, Fottler, & Unruh, 2003). Health status of family members has also been related to health plan preferences and choices.

#### Evidence

Very little research was identified that examined differences in health status based on stage of illness. Most studies refer to self-rated healthiness or specific health factors. A decision aid for hormone replacement therapy (HRT) was tailored based on menopausal and hysterectomy status, prior HRT, and breast cancer risk (Bastian, 2002; McBride, 2002). Women receiving the tailored information were more confident about making a decision about HRT at the one and 9-month follow-ups and were more likely to have an accurate perception of their breast cancer risk. The tailored information also resulted in increased satisfaction with their decision at one-month follow-up (but not 9-month) compared to those women who received standard information. However, of those women who were happy with their HRT decision at one month, those receiving the tailored information were more likely to remain satisfied at 9-months.

In a study on factors influencing participation in mammography screening, tailored letters based on patient health status using the Prochaska model of likelihood of taking action (precontemplation, contemplation, action, or maintenance) and tailored with photos of same race models were more likely to be remembered than standard letters (Skinner, 1994). Movement across stages and mammography screening rates were not affected for Caucasian women, but were positively affected for African American and low income women.

#### Measurement

A single item measure of perceived health status has been used in research (Settersten, 2004): "How would you rate your overall health at the present time?" Participants rated their health on a 4-point scale ranging from 1 (poor) to 4 (excellent). The validity and reliability for single-item ratings of perceived health status were established in Rand's Health Insurance Study (Ware, 1978). The Personal Lifestyle Questionnaire is a 24-item scale used to identify positive health practices (Yarcheski, 2004).

Other measures have been utilized in the assessment of health plan choice, for example, in the Fowles et al study of health plan selection, the self reported health status measure included items related to health care utilization including treatment for chronic condition, hospitalization, visits and anticipated medical care. Atherly, Dowd and Feldman used self reported health status (on a 5 point scale excellent to poor) and a score for the number of chronic illnesses present (although they asked about 8 chronic conditions they modeled their results using only the 4 with the largest marginal effect on costs (diabetes, arthritic, angina pectoris and hypertension)). Rather than self report, Strombom, et al. utilized hospital discharge and cancer registry data as measures of chronic illness (Strombom et al., 2002). Other studies have included family health status in this measure as well e.g. (Risker, 2000; Schur & Berk, 1998).

#### **Stability**

Health status may be relatively static or change rapidly with a new diagnosis. Perceived health status may vary relative to the comparison group (e.g., compared to same age elder peers vs. young adults).

#### Sensitivity

No special issues regarding sensitivity to health status were noted in the literature.

# Variable: Perception of Health Risks

#### Definition

The estimated perceived likelihood of getting a specific disease within the patient's lifetime.

#### Bottom Line

Perceived health risk of cancer is likely to be influenced by personal experience via family members with breast cancer (Rees, 2001). Personal experience varies significantly (positive role model vs. negative experience) and may override genetic counseling and/or other medical data (Rees, 2001). A family history of breast cancer may cause women to think in terms of the "costs" or "losses" of the disease with an increased likelihood to engage in unpleasant detection behaviors (Rothman, 1997). Perceived health risks may be based on social and cultural information rather than medical data and thus may be a barrier to making positive health changes (Wheeler, 2003). Although perception of health risks can motivate lifestyle/health changes, empirical findings are not consistent on whether health care messages should be framed in terms of "costs" (Rothman, 1997).

#### Evidence

An experimental manipulation regarding the risk and severity of colon cancer revealed that perception of risk was not increased, but those presented with information on the severity of the disease were more likely to be screened (Lipkus, 2003). The authors suggest that framing risk/severity information in terms of potential "losses" may be more motivational for changing behavior than information about what can be "gained." Patients with diabetes were generally unaware of their elevated health risk of cardiovascular disease and their perception of risk was not consistent with established medical data (Carroll, 2003). Men with a family history of prostate cancer had higher perceived risk and were more likely to have past and future intention for screening (Jacobsen, 2004). Cancer survivors did not have an exaggerated perception of risk of recurrence; low-level perceptions of risk motivated prohealth behaviors (Mullens, 2004). In that study, higher worry, anxiety, and perceived risk were associated with intention to change behavior positively. Family history increased the perceived risk for breast and colon cancer, heart disease, and diabetes in a random sample of people at a medical center cafeteria, but there was no effect of family history on perceived risk of prostate cancer for men, likely due to the small sample size (Montgomery, 2003). For females only in that study, friend history also increased perceived risk of breast and colon cancer, heart disease, and diabetes. The perceived probability and perceived severity of disease interact in motivating protective health behaviors, although the interaction is often hard to detect in between-subjects designs and individuals tend to ignore probability differences in the moderate to high probability range (i.e., 50-80%) (Weinstein, 2000). Health educators may need to address and provide education for moderate to high probability risks (e.g., genetic counseling) to help patients appreciate the true differences.

#### Measurement

There is a no gold standard to measure perceived risk (Lipkus, 2003). Researchers often use either or both a verbal method (likelihood of getting a specific disease: "no chance, very unlikely, unlikely, moderate chance, likely, very likely, and certain to happen") and a numerical scale (0% to 100% risk) (Lipkus, 2003). A study on cancer risk perception found that rating of perceived risk varied depending on the order of questions asked about personal and population risks for cancer (Taylor, 2002). In that study, perception of health risk was lowest when comparative ratings (comparing own risk with population risk) were assessed first. Most studies on perceived risk of disease have been done on women relative to breast cancer (Montgomery, 2003). Factors that affect risk perception include availability (more salient information is deemed more likely), representativeness (judgments

often based on similarity/stereotypes), anchoring and adjustment (people have a general conception of risk that may be adjusted after receiving specific risk information), and genetic risk and bias (patients often have misconceptions about inheritance) (Rees, 2001).

#### **Stability**

Likely to vary based upon how the message is framed (losses vs. gains) (Rothman, 1997) and depending upon specific disease risk.

#### **Sensitivity**

Since personal experience (i.e., familiarity via family or friend experience) of breast cancer may be as important or more important than medical data, it may be important to ask about family/friend medical history but this raises confidentiality issues.

# Variable: Health Behavior

#### Definition

There is no standard, agreed upon definition for "health behavior", but it's often used to refer to activities that have a direct impact on the health and wellness of individuals, including dietary habits, activity / exercise levels, and use of alcohol, tobacco or illegal drugs. It is occasionally broadened to include things like seatbelt use, sexual practices, weapons ownership / use, driving habits, and/or adoption of preventive health services / recommendations.

#### Bottom Line

There is scant evidence in the literature to argue strongly in favor of including an assessment of health behaviors in our survey from the standpoint of optimizing the creation and delivery of effective health education. It may, however, be useful to look at some of these behaviors and how they correlate with learning style, literacy, health literacy, SES, communication channel preferences, etc., but this would be of secondary interest. It would likely be publishable, however, based on some of the recent literature that seems to be emerging. Additionally, it may help to target preventive health efforts by knowing in which segments individuals who practice poor health behaviors reside.

#### Evidence

I could find no direct evidence that knowing a person's (or groups) health behaviors would help to improve the effectiveness of health education in a general way. Most literature that studies the link between health education and health behavior examines the effectiveness of a particular intervention for a particular health behavior, sometimes in a *particular population*, and measures knowledge, attitudinal, or behavioral changes related to that specific domain.

The closest approximation found in the literature occurs in the past 1-2 years, with a small number of researchers exploring the relationship between media channels, health behaviors, health attitudes/beliefs, and information sources (Dutta-Bergman, 2004). One such article suggested that individuals who practiced unhealthy behaviors were better targeted with "passive media outlets" like TV and radio. There is indeed ample evidence that suggests that television campaigns have been effective at reducing tobacco and marijuana use by adolescents. Other studies, more in the health education literature than the health communications literature, suggest that specialized interventions using peers as models / sources of information are more effective at reducing risky behaviors, e.g. related to intravenous drug use.

There is related literature that documents the relationship between risky behavior and "sensation seeking" personality traits, in which researchers note that individuals who undertake risky behaviors such as drug use, dangerous driving, or unsafe sex practices score higher on scales meant to measure sensation seeking. Health communicators have used this information to create public service announcements targeting these individuals, using ads that are dramatic, suspenseful, fast-paced and emotionally powerful (Palmgreen, 2001).

#### Measurement

In general, while measuring specific health behaviors is not terribly difficult, there are few established standards or guidelines for how to do so. One challenge is clearly related to the decision of which health behaviors to assess given the large range of possibilities. Glasgow et al have recently conducted an extensive review of measures used to assess 4 health behaviors – cigarette smoking,

eating patterns, physical activity, and risky drinking (Glasgow, 2005). They recommend a 22 item scale for adults but acknowledge that perfect measures are still hard to find.

#### **Stability**

Like everything else, this depends on which health behavior is of interest, but by and large, one important reason there is so much attention paid to behavior change is that it is so hard to do, suggesting that they may be fairly stable over moderate periods of time.

#### **Sensitivity**

Again this varies depending on the behavior, ranging from probably not terribly sensitive (seat belt use) to very sensitive (drug use, sexual practices).

# Variable: Social Support

#### **Definition**

There is no consistent definition of social support (Ell, 1996; Hupcey, 1998). Hupcey (1998) lists 12 definitions, noting that it may not be definable as it is multidimensional or multifaceted. According to House et al (1988), social support is "the positive, potentially health-promoting or stress buffering aspects of relationships such as instrumental aid, emotional caring or concern, and information." (House et al., 1988) Various types of social support include a social network index, emotional support, tangible aid, perceived support, frequency of support, roles, and attachments. LaCoursiere (2001) (cited in Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2004) (Nguyen, 2004) also provided a definition of online social support: "…the cognitive, perceptual, and transactional process of initiating, participating in, and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability (Nguyen, 2004)."

#### Bottom Line

Moderate to high importance. Experts suggest that "social support affects health by influencing our health behaviors" (Heitman, 2004). Social support in those with chronic illness increases self-esteem and self-control, serves as a buffer for stress, creates a sense of well-being, provides a sense of mastery that decreases depression, promotes medical adherence, and enhances coping that promotes health (Heitman, 2004). It may also reduce negative emotional affects on immune system or neuroendocrine functioning (Berkman, 1995; Cohen, 1985; Taylor, 1999). Exploration of family relationships may yield information that could affect change of negative health behaviors for an entire family and promote health for the current and future generations (Heitman, 2004). Families are not necessarily sources of positive support and misguided or uniformed family support may have a negative impact on health or recovery (Ell, 1996). Since social support is important in maintaining and supporting health, we may want to consider adding a section in informational materials that discusses how to involve the patient's family in their health care or maintenance of positive health behaviors (e.g., "How to Tell Your Family;" "Ways Your Family Can Help.")

#### Evidence

Reviews list multiple studies that indicate that individuals, including medical patients, with a social support network that provides emotional and material/tangible support are healthier than those with fewer social supports(Cohen, 1985). Social support may provide a buffer against stressful events (buffering model) or may provide a positive and beneficial effect regardless of stress level (main-effect model) and research appears to support both models (Cohen, 1985). More information is needed on the interaction between social support and the stages of disease (e.g., crisis, chronic) (Penninx, 1996). Electronic support groups do not appear harmful, but a review of such studies failed to find robust evidence of positive effects although many of the studies had inadequate research design or lacked statistical power (Eysenbach, 2004).

#### Measurement

According to Taylor & Seeman, there is no gold standard for measuring social support, which has slowed progress (Taylor, 1999). There are three general ways to measure social support: 1) network measures (who & how many), 2) perception of available emotional or material support, and 3) satisfaction with support received (Taylor, 1999). Perceived support must be distinguished from received support as the former may be influenced by negative outlook/pessimism (Schreurs, 1997). However, a review of social support on the course of chronic disease indicated that perceived support

was more consistently related to a more positive health outcome (Penninx, 1996). The most difficult measurement issue is assessing family support in reaction to exacerbations and remissions of chronic disease (Ell, 1996). There are at least two good reviews of social support measures (see Ell, 1996(Ell, 1996)) and other measures are listed in various articles (Cohen, 1985; Heitman, 2004; Schreurs, 1997). Single item and few-item measures have been used (Cohen, 1985).

#### **Stability**

A greater degree of family cohesiveness may be more beneficial when dealing with serious illness than is healthy under optimal health conditions (Ell, 1996). This may vary across illness stages with greater cohesiveness more helpful during the acute stages and balanced cohesion better during the chronic stage. Illness may change family processes, thereby affecting the effectiveness of social support (Ell, 1996).

#### Sensitivity

Social support should not be assessed in the presence of significant others, but no other significant concerns.

# Variable: Self-Efficacy

#### **Definition**

- Self-efficacy is a construct most closely associated with Bandura's social learning theory: It can be thought of as consisting of both outcome efficacy (the belief that a specific behavior will lead to a specific outcome) and personal efficacy (beliefs about how capable a person feels about performing the behavior); both influence behavior change and maintenance (Strecher, DeVellis, Becker, & Rosenstock, 1986).
- <u>Behavior-specific efficacy</u>: While specific behaviors may best be predicted by specific cognitions (Strecher et al., 1986) as in the task-specific self-efficacy construct proposed by Bandura, it has been argued that there are times when it is important to be able to predict behaviors across a range of situations (Schwarzer, 1994), (as in the TEACH project). This has lead to more inclusive measures of efficacy:
- <u>Health self-efficacy:</u> After determining that health locus of control was only moderately correlated with health and health behaviors (Schwarzer, 1994), (Wallston, 1992) Wallston turned his attention to a generalized form of health self-efficacy and, with Smith, constructed a "perceived health competence" scale (Smith et al., 1995). Smith and Wallston believe that LOC beliefs are still important, and may moderate the relations between efficacy and behavior (Smith et al., 1995).
- <u>Dispositional or General Self-efficacy</u>: Schwarzer developed a 10-item scale measuring dispositional optimistic self-beliefs and perceived coping competence. It is unclear how such a generalized measure might compare against a health-related measure of efficacy such as perceived health competence, or to behavior-specific efficacy as initially defined by Bandura.
- Bonetti and colleagues compared Wallston's Multidimensional Health Locus of Control Scale to two measures of self-efficacy, Smith's Perceived Health Competence and Schwarzer's Generalized Self-Efficacy. Their results suggest that each measure is internally consistent and contributed uniquely to prediction of respondent's exercise behavior, anxiety, and depression (Bonetti et al., 2001).

#### Bottom Line

Stetcher and colleagues describe the relative potential usefulness of personal efficacy and outcome efficacy:

- Outcome efficacy is influential when health behavior is not difficult to modify but whose perceived outcomes are uncertain, such as medication adherence to control hypertension.
- Personal efficacy is important when the health behavior leads to a desired outcome but is difficult to change, such as when smokers wish to quit.
- Both outcome and personal efficacy should be considered when the consequences are uncertain and behavior change is difficult, such as increasing fiber intake to reduce cancer risk (Strecher et al., 1986).

# Evidence

• Behavior-specific Self-Efficacy

Market Segmentation on Self Efficacy and effects on Nutrition: Hertog and colleagues published the only research focusing on market segmentation strategies focusing on self efficacy (2 x 2 median splits on outcome efficacy [diet affects health], personal efficacy [dietary change is easy]). Their characterization of the four groups:

- Group 1: High response efficacy, High personal efficacy: Older, well-educated woman involved in community with no children at home.
- Group 2: High response efficacy, Low personal efficacy: Somewhat younger woman, with children at home, more likely in dual wage-earning family
- Group 3: Low response efficacy, High personal efficacy: "Puzzling cluster of individuals" resembling group 1 but more likely to be male, less educated, less involved in community.
- Group 4: Low response efficacy, Low personal efficacy: Younger, working-class men in dual wage-earner households. "Probably least likely to respond positively to a mass-mediated dietary change campaign." (p. 37) Suggest that this group be reached through their spouse, worksite, or church, whose legitimation might increase impact of message.

Researchers reported that they were unable to determine the information sources preferred by each segment, so the mass media campaign was designed to reach \*all four\* groups, with the contents of messages crafted to address the needs of all four segments (Hertog, Finnegan, Rooney, Viswanath, & Potter, 1993).

#### MK Notes:

- Results suggest that segmentation should take place first, then assessment of preferred information sources.
- Outcomes of this consumer health education segmentation strategy were not reported. I contacted the author but was unable to obtain this information. Literature searches and Web-of-Science reviews likewise were not effective for determining the outcomes.
- Hertog provides a listing of characteristics of effective segmentation schemes as applied to public health interventions (Hertog et al., 1993).
- Skin Cancer: College students with high behavior-specific self-efficacy reported that vivid treatments (made vivid through use of personal case stories or addition of photographs to text) to be more persuasive. For those with low self-efficacy, vividness did not make any difference (Block & Keller, 1997).

Tailoring on specific characteristics: research has focused on the effects of customizing health education based on a range of variables, including self efficacy (nutrition (Brug, Campbell, & van Assema, 1999; Brug, Glanz, van Assema, Kok, & van Breukelen, 1998; Brug, Steenhuis, van Assema, & de Vries, 1996; Kreuter, Bull, Clark, & Oswald, 1999; Kreuter, Oswald, Bull, & Clark, 2000), physical activity (Marcus et al., 1998), and skin cancer (de Nooijer, Lechner, Candel, & de Vries, 2004; de Nooijer, Lechner, & de Vries, 2002); see below for details) Dijkstra and DeVries have outlined a three-stage methodology for developing computer-tailored interventions (Dijkstra & De Vries, 1999), but there appears to be no consensus yet about the best methods for tailoring for a given segment of the population (de Vries & Brug, 1999).

Tailoring for nutrition education:

- Brug and colleagues (Brug et al., 1999) reviewed eight studies on tailored nutrition education. Tailoring was done based upon:
  - "individual behavior (dietary fat consumption, servings of fruits and vegetables per day, etc.), socio-demographic variables (sex, age, etc.), health status (cholesterol levels, blood pressure, etc.), and psychosocial factors like attitudes, self-efficacy expectations, perceived threat, and readiness for change" (p. 147).

• Among the research reviewed was Brug's own research (Brug et al., 1998; Brug et al., 1996), in which a total of 223 possible health-related messages were available for use in tailored communication.

Tailored education was "more likely to be read, remembered, and experienced as personally relevant compared to standard materials. ... Tailored nutrition education also appears to have a greater impact in motivating people to change their diet" (p. 145).

- In two studies, Kreuter and colleagues tailored health messages based upon **outcome efficacy** for various weight loss methods, **personal efficacy** for four weight loss activities, along with weight loss beliefs, motives, barriers, triggers, dietary habits and preferences, food shopping and preparation routines, preferences for sources of weight loss information, and preference for solo versus social learning activities (Kreuter et al., 1999; Kreuter et al., 2000).
- In the 1999 study (Kreuter et al., 1999), participants who received tailored materials had more positive thoughts about the materials, positive personal connections to the materials, positive self-assessment thoughts, and positive thoughts indicating behavioral intention than those who received either form of untailored materials.

In the later study (Kreuter et al., 2000), researchers considered the effects of non-tailored but goodfitting materials, and found that good-fitting, non-tailored materials performed as well or better than tailored materials for several cognitive, affective, and behavioral outcomes. Moderately-fitting and poorly-fitting non-tailored materials were consistently inferior to good fitting non-tailored, and the tailored materials.

While it is unclear from their research report how Anderson and colleagues tailored their health education intervention, these researchers found that nutrition-specific self-efficacy and physical outcome expectations mediated the effects of the tailored information on nutrition-related outcomes. In turn, physical outcome expectations mediated the effect of self-efficacy on the nutrition outcomes (Anderson, Winett, Wojcik, Winett, & Bowden, 2001).

Tailoring in nutrition education based on dietary habits (not tailored on self-efficacy) resulted in increased self-efficacy and greater knowledge of low-fat and infant feeding knowledge, compared with controls (Campbell et al., 2004).

- Tailoring to encourage physical activity:
  - Marcus and colleagues(Marcus et al., 1998) delivered tailored reports and self-help manuals promoting physical activity. Tailoring was done on "stage of motivational readiness for physical activity adoption," physical activity participation, self-efficacy, "decisional balance," and cognitive and behavioral processes associated with adoption of physical activity. Sedentary adults in both tailored and standard interventions reported significant increases in physical activity, with a significantly greater increase for those receiving tailored materials. Those receiving tailored materials out-performed those receiving standard materials on all primary outcome measures (minutes of activity per week, reaching recommended minimum activity criteria, and achieving the Action stage of motivational readiness for activity adoption).
- Tailoring for skin cancer education:
  - De Nooijer and colleagues (de Nooijer et al., 2004; de Nooijer et al., 2002) tailored based on a collection of factors related to early detection of cancer (behavioral intention, attitudes, social norms, self-efficacy, knowledge, and demographic variables).

- In (de Nooijer et al., 2002), participants receiving tailored information saved and discussed the information with others more frequently, were more appreciative of the information format and content, and were more likely to change attitude and behavior.
- When considering the effects of tailoring in (de Nooijer et al., 2004) over the short term, the tailored group "had more knowledge of cancer symptoms, more positive expectations of the advantages of early detection behaviors, and higher self-efficacy expectations toward passive detection" (p. 701) than the general info or control groups. After three weeks, the tailored group "expressed more positive intentions toward engaging in passive detection and help-seeking behavior" (p. 701). After six months, the tailored group was more positive in their intention to seek help and toward passive detection.
- Tailoring for smoking education:
  - Studies found did not tailor on self-efficacy (instead on name, number of cigarettes smoked daily, amount of money to be saved if respondent quit, number of years smoked), so not reviewed here (Dijkstra, de Vries, & Roijackers, 1998; Dijkstra, de Vries, & Roijackers, 1998).
- Self-efficacy has been an effective predictor of health behavior:
  - Strecher and colleagues reviewed research on the relationship of behavior-specific selfefficacy across the practice areas of smoking, weight control, contraceptive behavior, alcohol abuse, and exercise. While they note that few studies consider outcome efficacy (most focus on personal efficacy), they conclude that strong relationships exist between self-efficacy and behavior change and maintenance across these domains. Further, they note that "experimental manipulations of self-efficacy suggest that efficacy can be enhanced and that this enhancement is related to subsequent health behavior change" (p. 73) (Strecher et al., 1986).
  - Similarly, O'Leary's review suggests that self-efficacy is influential in smoking-cessation, pain experience and management, control of eating and weight, success of recovery from myocardial infarction and adherence to preventive health programs (O'Leary, 1985).
  - For adults with diabetes, personal efficacy was correlated with self-care in the areas of diet, exercise and blood glucose testing. Outcome efficacy was correlated with exercise and blood glucose testing. The relationship between personal efficacy and blood glucose testing was moderated by outcome efficacy, such that personal efficacy had a greater effect when combined with strong beliefs in outcomes. At low levels of personal efficacy, strong outcome efficacy beliefs were associated with poorer self-care (Williams & Bond, 2002).
  - In a study of 107 British adults, behavior-specific efficacy beliefs effectively predicted the target health behaviors (smoking, alcohol, exercise, diet, weight) for those respondents placing a high value on health (Norman, 1995).
- Perceived Health Competence

Perceived Health Competence (PHC) has been used in a variety of research inquiries where a measure of health-related self-efficacy has been desired. A "Web of Science" search yielded 30 studies referencing this measure. While PHC is frequently significantly predictive of health behavior, none of the studies involved health competence as an independent variable, so I did not review them.

• General Self-Efficacy

I did not find research in which generalized self-efficacy has been used as an independent variable. Schwarzer indicates this measure having been used in 20 studies, and reports that it has

been "a better predictor of subjective well-being, self-reported illness, and coping than other concurrent measures such as self-esteem and trait anxiety" (p. 172), though he notes that "it has not been determined whether a number of specific self-beliefs can be aggregated to one score of generalized self-efficacy" (p. 172-3).

In a more recent work General Self-Efficacy was used in a study of 418 female college students in Poland, where it emerged as the best predictor of behavioral intention and planning. Planning, in turn, appeared to be the best predictor of breast self-examination behaviors, followed by self-efficacy.

#### Measurement

• Behavior-specific SE scales:

Bandura suggests determining whether Ss believe a behavior can be accomplished and the strength of this belief. In most studies, subjects were asked how confident they would feel in performing the target behavior in different situations or mood states where the ability to perform the behavior might vary." (p. 88) (Strecher et al., 1986).

Nutrition

- Two SE subscales: Six-item Response Efficacy (perceived benefits of dietary change –which seems similar to the health value measures mentioned as an important mediator of LOC by Wallston) and Personal Efficacy (Hertog et al., 1993)
- Three subscales reflecting SE for increasing fiber and fruit and vegetables, decreasing fat in snacks, and decreasing fat in meals (Anderson et al., 2001).
- Five-item scale reflecting SE for consuming low-far dairy foods and snacks, consuming more fruits and vegetables, trimming fat from meats, and backing or broiling instead of frying (Campbell et al., 2004).

Physical Activity

• Five-item SE scale representing negative affect, resisting relapse, making time for physical activity (Marcus et al., 1998).

Skin cancer

- Single item on preventive behavior (Block & Keller, 1997).
- Eight items (SE for paying attention to cancer symptoms, seeking help for cancer symptoms, and four items reflecting SE for seeking help in different situations) (de Nooijer et al., 2004; de Nooijer et al., 2002).
- Perceived Health Competence Scale (PHCS) (de Nooijer et al., 2002)

An eight-item measure reflecting self efficacy for managing own health outcomes, adapted from a general measure of perceived competence developed by Wallston. Predictive of intended or actual health behavior but relationships here unclear. Uses a five-point response scale, ranging from "Strongly disagree" to "Strongly agree."

<u>Reliability</u>: Internal consistency has ranged between 0.82 and 0.90. Test-retest between 0.82 for one week interval to 0.60 for 2.5 years.

<u>Validity</u>: PHCS significantly correlated with general health status (correlations 0.4 to 0.5), significantly correlated with locus of control in positive directions, significantly correlated with an active coping style and measures reflecting positive well-being and mental adjustment, negatively correlated with measures indicating poor adjustment.

• General Self Efficacy (Schwarzer, 1994)

A ten-item measure (constructed in German) assessing dispositional optimistic self-beliefs and coping competence. Includes typical items such as, "When I am confronted with a problem, I usually find solutions," and "I remain calm when facing difficulties because I can rely on my coping abilities."

#### **Stability**

- Self-efficacy has been employed as a predictive valuable for behaviors including smoking, weight control, contraceptive behavior, alcohol abuse, nutrition, exercise, and skin cancer prevention.
- As reported above, for Smith's Perceived Health Competence scale, stability over one week was 0.82 and over 2.5 years was 0.60.

#### Sensitivity

• Self-efficacy is socially acceptable—no reports of sensitivity from respondents noted in research reports.

# Variable: Locus of Control

#### **Definition**

- Julian Rotter developed a particular flavor of social learning theory, and within it defined the construct of locus of control (LOC). LOC connotes the degree to which an individual expects that events are influenced by his/her own behavior (internal control) or by external factors beyond one's control, such as "powerful others" or chance (external control) (Rotter, 1966).
- Within the health domain, researchers such as Wallston and colleagues (Wallston & Wallston, 1978; Wallston, Wallston, Kaplan, & Maides, 1976; Wallston, Maides, & Wallston, 1976; Wallston et al., 1983; Wallston et al., 1978) built on Rotter's work to develop health-related LOC scales (HLC and MHLC). Research using this measure suggests that internals are most likely to perceive that their behaviors lead to valued health outcomes, and to engage in the health behavior to achieve these outcomes.
- Wallston contends that LOC should be measured along with a measure of Health Value, as high internality may be reliably predictive of positive health behavior only when the outcome is valued (Smith & Wallston, 1992; Wallston, 1991). A commonly used measure of health value is the Rokeach Value Survey developed by Milton Rokeach (1973, 1979), who defines health value as an enduring belief that specific behaviors or outcomes are socially preferable to the opposite behaviors or outcomes. (Armitage reports using the Lau & Ware Health Value Scale (Armitage, 2003)) According to Allison (Allison, 1991), Laglie (1977) reports that, of the factors examined, Internal LOC and perceptions of high benefits/low cost/both had highest predictive value for preventive health behavior.

#### Bottom Line

By itself, locus of control may not be a particularly strong predictor of behavior. After fifteen years of substantial research on LOC, Wallston (primary researcher in health-related LOC) notes that,

"Even when one selects only those persons who value their health highly and even when the dependent variable is an index of health behaviors rather than a single behavior, the amount of variance in health behavior explained by HLC beliefs is relatively small" (italics supplied by author, p. 186) (Wallston, 1992).

Armitage suggests that the problem may be that researchers have attempted to use a generalized measure (such as Wallston's MHLC) to predict specific behavioral outcomes, and that such a measure might be more appropriately used to predict "clusters of goals, expectancies, and values in driving social and health behaviour," (p. 725) (Armitage, 2003). An example of the ineffective use of the generalized MHLC to predict specific behaviors can be found in Norman's study of 107 British adults: Only behavior-specific efficacy beliefs predicted the target health behaviors; MHLC did not correlate significantly with any (Norman, 1995).

Instead of using LOC alone, Wallston suggests that LOC may be a mediating variable between selfefficacy and behavior. In fact, research findings indicate a place for LOC:

• Bonetti and colleagues compared Wallston's MHLC to two measures of self-efficacy, Schwarzer's Generalized Self-Efficacy and Smith's Perceived Health Competence. Their results suggest that each measure is internally consistent and contributed uniquely to prediction of respondent's exercise behavior, anxiety, and depression (Bonetti et al., 2001). Research by Armitage suggests that, even after accounting for the stronger predictive effects of taskspecific control, the more general multidimensional health LOC still contributed to prediction of behavioral outcomes (Armitage, 2003).

#### Evidence

- Wallston reports use of MHLC scales to predict knowledge and behavior in research on smoking; weight loss; knowledge about health conditions such as: TB, diabetes, and depression; medication adherence and appointment-keeping; venereal disease (Wallston & Wallston, 1978).
- Wallston and many other researchers have applied the MHLC to consideration of "health behavior" (prevention) and "sick-role behavior" (after diagnosis); there has been little research on the intervening "illness behavior" (after appearance of symptoms and before diagnosis) (Wallston & Wallston, 1978).
- In a study of different forms of patient education promoting screening mammograms, women receiving information consistent with their health locus of control beliefs were more likely to obtain a mammogram six and twelve months after the intervention than women who received information that was not consistent with their health locus of control orientation (Williams-Piehota, Schneider, Pizarro, Mowad, & Salovey, 2004).
- Holt and colleagues found that overweight internals (individuals with an internal locus of control orientation) who receiving tailored health information related to weight loss (tailored as per Kreuter's model, see Self Efficacy review) expressed fewer negative thoughts about that information than internals receiving non-tailored information, while no differential effects were noted for externals (Holt, Clark, Kreuter, & Scharff, 2000).
- (The above were the only two studies which employed different educational strategies for patients with different degrees of control. Researchers have explored tailoring of health information based on a range of task-related and psychosocial variables, locus of control has not been among them.)
- Hashimoto found that among internals in the general population in Japan, informational preference was positively correlated with decisional preference: An active information seeker was likely to be an active decision maker. Among externals, preferences for information and decision-making were negatively correlated: these individuals may use information for other purposes than decision-making, such as anticipating what is going to happen, or to be psychologically prepared for accepting the physician's decision (Hashimoto & Fukuhara, 2004).
- There may be cross-cultural differences between populations on locus of control. LOC may be mediated by health beliefs, behaviors, and outcomes; cultural esteem for sectors of the population (e.g., the aged); and environmental factors (Stein, Smith, & Wallston, 1984).
  - For instance, data from 1541 independently living older persons in the Netherlands suggests that the level of perceived control decreased and the level of disability increased significantly over an 8-year period.
  - (This pattern is quite similar to that noted for preference for health care decision-making. See my report on this construct.)

#### Measurement

- Rotter offered an initial scale of 13 items (Rotter, 1966).
- Adolfsson and colleagues developed a Swedish LOC scale, modified from Rotter's I-E scale (Adolfsson, Andersson, Elofsson, Rossner, & Unden, 2005), and there have been forms developed in other languages as well.
- Wallston, et al., built on Rotter's work and conducted extensive measurement development research on the Multidimensional Health Locus of Control Scale (MHLC). They offer good psychometrics for this scale. There are three subscales of six items each (Internal, Powerful Others, and Chance). For each sub-scale there are two versions, A and B (Wallston et al., 1978).
- See Hashimoto's five-item Powerful Others LOC scale (Hashimoto & Fukuhara, 2004).
- Kempen, et al. report a 7-item "mastery scale" developed by Pearlin and Schooler with internal reliability estimates of 0.71 and 0.79 and eight-week test-retest reliability of 0.67.
- For example of a Health Value scale, see the Lau & Ware (1981) scale used by Armitage (Armitage, 2003).

#### **Stability**

For Pearlin and Schooler's Mastery scale, Kempen reports eight week stability at 0.67 but also reports that, for independently living older people, the level of perceived control decreased and the level of disability increased significantly over an eight-year period (Adolfsson et al., 2005).

#### **Sensitivity**

Locus of control is socially acceptable—no reports of sensitivity from respondents noted in research reports. However, a possible "sticky issue" noted by Wallston concerns our possible future work with those diagnosed with diabetes: Individuals who consider themselves internals may have more difficulty continuing to wield the control they normally perceive, if their diabetes is difficult to manage or is unpredictable.

# Variable: Decision-Making Preference

#### **Definition**

- Roles in health care decision making "range from playing an active role, in which an individual makes their own decisions, through a collaborative or sharing role, to a passive role in which the physician or other health care professional is the primary or sole decision maker" (p. 9) (Beaver et al., 1996).
- Shared Decision Making (SDM) has been defined as "occurring when a patient and his or her healthcare provider(s), in the clinical setting, both express preferences and participate in making treatment decisions" (p. 68) (Briss et al., 2004).
- SDM is a sub-set of Informed Decision Making (IDM): "occurring when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision-making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time" (p. 68) (Briss et al., 2004).

#### Bottom Line

I did not identify any studies in which patient education was developed for patients of differing decision-making preference.

Regardless of patient desire for participation in decision making (which varied across studies, see below), most study respondents indicated a desire for information(Guadagnoli & Ward, 1998):

- Research conducted by Ende(Ende, Kazis, Ash, & Moskowitz, 1989) and Neame(Neame, Hammond, & Deighton, 2005) suggest no correlation between patients' decision making and information-seeking preferences (r = 0.09; p = 0.15).
- Providing any treatment description at all to elderly patients "resulted in greater acceptance of treatment for all comorbid situations." ((Ainslie & Beisecker, 1994) p. 2231)
- Women with breast cancer welcomed being given clear information about the options available, together with the reasons as to why a clinician would advise one policy rather than another. Fewer women than expected wished to take a major role in decision-making about their breast cancer treatment(Fallowfield, 1997).

Information exchange is considered to be the first phase in treatment decision-making, followed by deliberation about treatment options and the decision on treatment to implement(Charles, Gafni, & Whelan, 1999).

Therefore, it may be most useful to focus on Desire for Information.

#### Evidence

In the research on patient preferences for decision-making, "the severity of the patients' conditions, and their being older, less well educated, and male are predictors of a preference for the passive role in the doctor-patient relationship" ((Benbassat, Pilpel, & Tidhar, 1998), p. 81).

• The majority (69%) of 22,462 chronically ill patients preferred to leave their medical decisions to their physician. Younger patients, Women, more highly educated patients, and those with less-severe illnesses were found to have greater preference for an active role in decision-making(Arora & McHorney, 2000).

- The majority (59%) of cancer patients wanted physicians to make treatment decisions on their behalf, but 64% of the general public thought they would want to select their own treatment if they developed cancer(Degner & Sloan, 1992).
- The majority of patients studied by Ende and colleagues expressed a decreasing desire to make decisions as they faced more severe illness. Older patients had less desire than younger patients to make decisions and to be informed (p less than 0.0001 for each comparison) (Ende et al., 1989).
- Decision preference was more likely seen among individuals with (1) younger age, (2) higher educational background, (3) female gender, and (4) less attribution to "Others" (Hashimoto & Fukuhara, 2004).
- Among patients with rheumatoid arthritis, the Need for information and for decision making were both higher in women than men(Neame et al., 2005).
- A majority of the Australian young people with cancer (12-24 years) wished to be more involved in treatment decisions(Hashimoto & Fukuhara, 2004).
- Across cultures and ages, Bennet, et al. (Bennett, Smith, & Irwin, 1999) found a distinct preference for participation in decision-making.
- Women from various cultural groups in the general population expressed a strong desire to be involved in elective treatment decisions(Groff et al., 2000).
- "The majority of healthy women surveyed by Helmes and colleagues preferred to make their own health care decisions. Predictors were education, knowledge, and locus of control(Helmes, Bowen, & J., 2002)."
- However, the elderly in one study indicated a preference for decisions to be made by "self" or "self and doctor together (Ainslie & Beisecker, 1994)."

Demographic variables appear to be only modestly useful in predicting preferences for decision making:

- Socio-demographic variables accounted for only 15% of the variance in preferences (Degner & Sloan, 1992).
- Only 19% of the variance among patients for decision making and 12% for information seeking could be accounted for by stepwise regression models using sociodemographic and health status variables as predictors (Ende et al., 1989)."
- Nonsignificant predictors of decision making preference included: race, will to function, active lifestyle, employment status, marital status, income, health distress, and social support (Arora & McHorney, 2000).

The preference for decision-making is likely influenced not only by control and efficacy orientations but also by perceptions of medical expertise and the perceived importance of the health care decisions:

- The majority of women newly diagnosed with breast cancer preferred to play a passive role in treatment decision making, leaving the decision-making responsibility to their physician, whereas the benign control group preferred a collaborative role in which joint decisions could be made between the patient and the physician (Beaver et al., 1996).
- Patients with higher perceived health value were less likely to prefer an active role (Arora & McHorney, 2000).

Finally, the way patients respond to decision-making preference measures can be different from their actual behavior (Entwistle, Skea, & O'Donnell, 2001).

# Measurement

• Autonomy Preference Index, 23 items (Ende et al., 1989).

- Adapted Autonomy Preference Index, 18 items(Bennett et al., 1999).
  - Card sort procedure developed by Degner and Sloan (1992):
    - MK NOTE: Obviously format not well-suited to telephone survey
    - Two sets of five cards each. Each card describes a different role in decision making and is illustrated with a cartoon.
    - The first set of five cards (patient/physician dimension) illustrated roles that the patient and physician would assume, ranging from the patient selecting his own treatment, through a collaborative model, to a scenario where the physician alone made the decision.
    - The second set of five cards is designed to indicate whom the patient would want to make treatment decisions on his behalf if he became too ill to participate. These options ranged from the patient's family making the decision alone, through a collaborative model where the family and physician jointly decided, to a scenario where the physician made the decision alone (Degner & Sloan, 1992).

#### **Stability**

There have been insufficient reports of the use of the above measures to make any observations on stability over time and across situations.

#### **Sensitivity**

There do not appear to be any negative issues associated with use of this construct within research.

### Variable: Cognitive Ability/Limitations

#### **Definition**

Limitations in cognitive ability may be specific, such as memory impairment, or global, such as mental retardation (MR). May include patients with dementia or medical conditions that affect cognition. Cognition includes general intellectual ability, learning, verbal and visual memory, ability to process information rapidly, attention, concentration, and the ability to organize information. Some of the European/Australian literature uses the term "intellectual disability" or "learning disability" to refer to mental retardation.

#### Bottom Line

High importance. Cognitive limitations will affect patients' ability to comprehend and utilize health care information. Patients who are non-adherent may not understand or remember medical instructions. Barriers to health care for cognitively limited patients may be informational, physical, or behavioral (Glassman & Miller, 2003). One of the goals of the federal Healthy People 2010 is to eliminate health disparities for people with disabilities (Ewing, 2004). The health needs of people with MR are not addressed, although they are often at higher risk for many chronic diseases (Jobling, 2001). The health system relies on patients to monitor, recognize, and report medical symptoms, which is often problematic for individuals with cognitive limitations (Turner & Moss, 1996). Cognitive limitations may also affect the growing senior citizen population (Glassman & Miller, 2003).

#### Evidence

Most of the studies conducted in this area are methodologically flawed with small samples sizes and inadequate control groups. The publications primarily address the importance of serving this population and modifying communication and materials, but there are very few empirical studies. Most of the studies also specifically target individuals with mental retardation without reference to individuals with milder cognitive impairment, who may not be readily identifiable (e.g., borderline intellectual functioning). One study examined cognitive impairment as determined by the MMSE and found that it affected medical decision-making in an elderly group (Fazel, Hope, & Jacoby, 2000). Neurocognitive functioning was also examined in patients with alcohol abuse or dependence and memory performance was found to predict readiness to change drinking behavior (Blume, 2005).

Various interventions have been attempted to improve health care for individuals with mental retardation. A daily journal for recording medical information was developed for individuals with mental retardation to enhance communication with health care professions, but adequate information on how the diary affected/improved health care behaviors was lacking (Lennox, 2004). A special clinic day was created for women with MR with greater emphasis on longer appointments to allow for additional education and support. A smoking cessation program was modified to reduce literacy requirements and level of abstraction for individuals with MR and increased health awareness (Tracy & Hosken, 1997). One study found that an information brochure on medication was less effective than no leaflet, but the study involved multiple clinicians and the brochure had flaws (Strydom, 2001). An 8-week health education group for "normal learners" and patients with MR revealed that both groups demonstrated a positive outcome, although the normal learners had a greater degree of change from pre- to post-testing (Ewing, 2004).

One interesting study used an exercise and health curriculum based on Bandura's social cognitive theory of social learning and Prochaska's model for adults with Down syndrome (Heller, 2004). They incorporated peer trainers, group training, videos, and personalized workbooks to emphasize

social modeling with positive outcome, but the study was flawed because the control group had no training. As a result it is unclear if the positive outcome was due specific to the intervention or to the Hawthorne effect.

#### Measurement

While formal IQ testing is generally valid and reliable, it is time consuming and expensive. This is also true of other neurocognitive functions (e.g., learning and memory) although there are some computer-based tests that are less time intensive. Except for those patients with documented MR, it is difficult for staff to identify cognitive limitations in patients and this may result in misunderstandings and miscommunication (Black, 2004).

#### **Stability**

While intellectual ability is generally stable, other cognitive abilities may fluctuate depending on medical and psychological status.

#### **Sensitivity**

Individuals with cognitive limitations may be embarrassed to admit to these and may attempt to minimize or hide their difficulties. It may be helpful to phrase questions about cognitive limitations under the guise of "learning styles."

# Variable: Reading Literacy

#### Definition

"Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential. Includes prose literacy, document literacy, and quantitative literacy." The latter is defined as "the knowledge and skills required to apply arithmetic operations, either alone or sequentially, using numbers embedded in printed materials" (Kirsch, 1993). Additionally, literacy should be viewed as a continuum rather than a dichotomous variable (Weir, 2001). The U.S. Census bureau defines literacy as reading at the fourth grade level (Weiss, Hart, McGee, & D'Estelle, 1992). Individuals with low-literacy may make literal interpretations and have a cognitive style that is concrete and focused on the immediate (Center, 1994).

#### Bottom Line

Extremely high importance. Fifty percent of the US has rudimentary to limited reading skills. According to the National Adult Literacy Survey (Kirsch, 1993), 21-23% of the population is at the lowest literacy level, depending on the type of literacy. The average reading level of American adults is between the 8<sup>th</sup> and 9<sup>th</sup> grade levels, but the average reading level for Medicaid patients is at the 5<sup>th</sup> grade level(Health, 1998). Health status is correlated with literacy, even after accounting for nutritional status, employment, educational status, and income (Health, 1998). Reading level is correlated with both physical and psychosocial health (Weiss et al., 1992). Lack of patient adherence is a huge problem in health care and may actually reflect low-literacy (Kleinbeck, 2005). Low literacy does not appear to limit access to health care, but may indicate poor understanding of medical instructions (Baker, Parker, Williams, Clark, & Nurss, 1997) and does not always translate into increased health care costs for Medicaid recipients (Weiss et al., 1994).

#### Evidence

According to the NALS, contributing factors to the lowest level of literacy included immigration, low education, non-Caucasian race/ethnicity, age 65 or older, and physical, mental, or health condition that impaired functioning (Kirsch, 1993). In a sample of literate and illiterate patients with rheumatoid arthritis, illiteracy was associated with increased hospital visits despite equivalent health function suggesting that illiterate patients may require additional hospital visits in order to compensate for their illiteracy (Gordon, 2002).

The National Work Group on Literacy and Health (1998) reviewed studies and found only three studies that examined the correlation between health status and literacy in the US and these revealed 1) that participants with the lowest literacy had the worst psychological and physical health, 2) "Medically needy or medically indigent" Medicaid participants with poor literacy skills had significantly higher health care costs, and 3) patients with lower literacy had higher health care utilization.

A few studies have empirically assessed the use of modified patient education materials for lowliteracy patients. The use of pictographs dramatically improved recall of medical information in patients with low-literacy in a cross-over design (Houts, 1998). Notably, the lowest percent recall with pictographs (55%) was better than the lowest percent recall (32%) without pictographs. The authors suggest that illiteracy be viewed as a memory problem and that learning and memory research be used to guide the development of education materials for low-literacy patients. This is particularly important because audio taped materials may overly tax the cognitive abilities of low-literacy patients. Although it lacked a control group, a study that devised materials emphasizing a colorcoded system (green, yellow, and red light) to inform low-literacy patients when to contact medical

staff yielded a statistically and clinical significant improvement in symptoms of heart failure and resulted in 100% high patient satisfaction (DeWalt, 2004). A literacy review on the efficacy of using video for patient education revealed that video is equivalent to other methods for long-term retention of knowledge, may have advantages for low-literate populations, and appears to reduce stress associated with medical procedures via modeling. A study of patients with colon cancer revealed that a booklet and video were equivalent in informing patients, but both had been tailored to the population with attention to literacy issues and ethnic diversity (Meade, 1994). The expertise of marketing experts in conveying information was demonstrated in a study in which patients were randomly assigned to view either an animated cartoon video created by marketing experts or to read standard medical literature on polio vaccine (Leiner, Handal, & Williams, 2004). Despite equivalent knowledge on the pre-test, the groups diverged significantly at posttest. Notably, approximately 30% in the video group attained a perfect score on the posttest, while none in the control group did so.

#### Measurement

Research has indicated that actual reading ability is about four to five grade levels below reported years of education (Doak, 1996; Meade, 1994). There are a variety of tools for assessing reading literacy with generally good psychometric properties, but they are generally time consuming with a few exceptions. The REALM was developed to assess literacy for medical information.

#### **Stability**

Reading literacy is fairly stable across time with the exception of those who enter adult reading classes. There are types of literacy (e.g., prose, document, quantitative) that may produce assessed differences across situations.

#### Sensitivity

Many patients with low-literacy are afraid that their illiteracy will be discovered and make attempts to evade detection. In a small study of eight patients with no or limited reading ability who had recently been hospitalized, all participants felt that literacy screening should occur in hospitals, although may felt that they would be very embarrassed and would not volunteer information about their literacy issues (Brez, 1997). Two patients indicated that they would refuse literacy screening. The Health Belief Model was used to discuss the risks and benefits of disclosing illiteracy versus the potential for adverse consequences of hiding illiteracy. In the NALS, a large majority of patients said they were able to read English well, yet they fell within the lowest literacy group on formal testing indicating a significant discrepancy between self-reported literacy and literacy assessed via objective testing (Kirsch, 1993).

# Variable: Learning Styles

#### **Definition**

The preferred method by which individuals process information, which may change over time (Arndt, 1990). According to Dunn & Dunn (1973), "learning style is a biological and developmental set of personal characteristics that makes identical instructional environments, methods, and resources effective for some learners and ineffective for others" (Van Wynen, 2001).

There are multiple descriptions of learning styles, including the Index of Learning Styles (active/reflective, sensing/intuitive, visual/verbal, and sequential/global), Curry's Onion Model (personality dimensions, information processing, social interactions, and multi-dimensional or instrumental preferences), Learning Style Survey (auditory linguistic, auditory quantitative, visual linguistic, visual quantitative), field independence or dependence (Higgins, 1988), Kolb's learning styles (divergent, assimilative, convergent, accommodative)(Arndt, 1990), Dunn and Dunn (21 elements contained in "five strands" & includes perceptual style: auditory, kinesthetic, tactual, visual) (Van Wynen, 2001), Canfield's Model (8 variables) (Merritt, 1991), etc.

#### Bottom Line

Low due to the multiple definitions of learning style and the lack of empirical studies validating the learning styles in patient populations. According to Kolb, the learning process should start by examining the theories and beliefs held by the learner on specific topics (Arndt, 1990). This may have relevance for health care consumers in terms of health beliefs and updating knowledge about chronic disease states. John (1988) coined the term "geragogy" to describe learning for older adults and strategies include short presentations with concise summation, practical topics, avoidance of abstraction, minimization of rote memory demands, a warm and friendly atmosphere, and use of reinforcement, encouragement and praise (cited in Van Wynen, 2001) (Van Wynen, 2001).

#### Evidence

Very little empirical research is available on learning styles in patient education. A PsychInfo search from 1872 to 2005 revealed 1582 references on "learning style" and 8003 on "health education;" combining the data sets yielded 9 references. Most of the hits on Medline (n=246) for "learning style" pertained to the education of nursing or medical students and were not pertinent to patient education. A critical review of learning style research indicated that there is a lack of definition and consensus, that most studies of the topic are methodologically flawed, and that focusing on learning style may ignore other important learning factors. A patient designed educational intervention for hyperlipidemia that incorporated patient-preferred learning style of informal, interactive formats did not enhance learning compared to an expert designed intervention and neither improved cardiovascular risk behaviors (Dobs, 1994). Health education for older adults has typically focused on illness rather than wellness and there is little research on wellness education for this group (Van Wynen, 2001). A relatively small study revealed that older adults prefer a traditional, structured learning environment with an authority figure and the opportunity to interact with peers (Van Wynen, 2001). A study that examined learning preferences of patients with coronary artery disease indicated that they wanted organized information with detailed content and how to achieve learning goals with a preference for active participation and visual and oral instruction components (Merritt, 1991). A survey of underserved and uninsured medical patients revealed that they preferred "hands-on" learning over reading and listening (Kessler & Alverson, 2003). A review of research suggests that patients prefer group learning over individual learning for diabetes education (Walker, 1999).

#### Measurement

A videodisc Learning Style Survey (LSS) was validated against the Hill Cognitive Style Interest Inventory with a Pearson correlation of .68 and a test-retest for the LSS of .78 and may have potential for low-literacy populations (Gretes & Songer, 1989). The Solomon/Felder Index of Learning Styles is available online at <u>http://www.ncsu.edu:80/effective\_teaching?ILSpage</u> and has test-retest reliability "over 90%"(Lohri-Posey, 2003). The Patient Learning Style Questionnaire (is based on the Canfield Model and construct validity was established by factor analysis and has 15 demographic items and 72 learning items (Merritt, 1991). Measurement of this variable is very tricky given the preponderance of definitions and methods of assessment.

#### **Stability**

Difficult to assess given the multiple definitions and measures.

#### Sensitivity

No concerns, but literacy may affect learning style preference.

# Variable: Health Literacy

### Definition

"Health literacy is the degree to which individuals can obtain, process and understand the basic health information and services they need to make appropriate health decisions"

Health literacy comes from a convergence of education, cultural and social factors, and health services. While reading, writing, math skills make up a part of the basis of health literacy, many other skills/abilities are important such as speaking, listening, having adequate background information and being able to advocate for oneself." (2010, 2000; Ratzan & Parker, 2000; Selden, Zorn, Ratzan, & Parker, 2000)

- Health Literacy is mediated by education, culture and language
- Health literacy is needed in a wide variety of "health contexts"

#### Bottom Line

Include Health Literacy. Why?

- <u>There is significant interest in HL by the leading medical agencies & the government.</u> In the Institute of Medicine report on Health Literacy, Recommendation 6-3 states: "HL assessments should be a part of healthcare information systems and quality data collection. Public and private accreditation bodies, including Medicare, the National Committee for Quality Assurance, and JCAHO should clearly incorporate health literacy into their accreditation standards."
- 2. <u>Health literacy is a very well cited construct with few experimental studies associated with its impact.</u>

Of the approximately 200 articles that mention health literacy, very few (10-15%) actually measure the association of health literacy with outcomes and almost none attempt to modify health literacy.

3. There is mounting information that health literacy is related to relevant health outcomes.

#### Evidence

"Although causal relationships between limited health literacy and health outcomes are not yet established, cumulative and consistent findings suggest a causal connection" (Nielsen-Bohlman, Panzer, & Kindig, 2004).

Multiple studies (approximately 30) have linked low health literacy to self-reported poor health status, poor health behavior and inadequate knowledge about disease. Many of these studies have found relationships even while controlling for other potential confounding factors. These studies are listed below:

Current evidence of the effect of low health literacy on consumer health				
General Outcome	General Outcome Specific Outcome Reference			
Health knowledge	Knowledge of chronic disease	Gazmararian, Wallace		
	Less knowledge about effects of smoking on	Arnold, 2001		
	baby			

	4 times more likely to have incorrect knowledge about when to get pregnant	Gazmararian
Health behaviors	Pregnancy Preparedness	Endres, 2004
	Reported limited access to care	Baker
	Adherence to medication; surgical instructions	Chew, 2003
Decision making & Communication	Worse communication with physician	Schillinger, 2002
Health status & outcomes	Poorer diabetes outcomes	Gazmararian
	Self-report of worse health status	Baker, 1997, 2002
	More likely to be hospitalized	Baker et. al., 1998
	More likely to present with worse grade prostate cancer	Bennett et. al., 1998

#### Ease of Measurement

The greatest challenge will be measuring health literacy. There are 2 primary measures used to assess Health Literacy. Both measures focus on the more traditional aspects of literacy measurement (reading skills; word recognition; numeracy) without including broader factors considered necessary to be health literate.

- REALM Rapid Estimate of Adult Literacy in Medicine(Davis et al., 1993) is a medical word and pronunciation test. Respondents are asked to read from a list of health and medical terms that are increasingly more difficult. The test can be administered and scored in three minutes. The REALM correlates well with other standard reading tests and has high intrasubject reliability. \*A shortened REALM (8 items) has also been developed and looks promising(Bass, Wilson, & Griffith, 2003).
- 2. S-TOFHLA Short Test of Functional Health Literacy in Adults (Parker, Baker, Williams, & Nurss, 1995) is a 4 item test of numerical ability with a 36 item test of reading comprehension. It can be completed in 12 minutes or less. It has good internal consistency and correlates well with the REALM.

#### **Stability**

There is no work in examining the stability of health literacy over time. However, one might imagine that health literacy might change over time and might be particularly impacted by the diagnosis of a new condition. The stability of health literacy should be considered.

#### Sensitivity

There is some shame associated specifically with health literacy that needs to be considered related to measurement. People with low literacy skills (like HL) might be ashamed to speak up (Baker et al., 1996; Parikh, Parker, Nurss, Baker, & Williams, 1996).

# Variable: Numeracy

#### **Definition**

Quantitative literacy, the ability to handle basic probability, mathematical and numerical concepts.

#### Bottom Line

Inconclusive.

#### Evidence

Numeracy impacts informed decision making, level of compliance, understanding of risk and measures of utility. Perhaps over half of the population has low numeracy.

Warfarin treatment reduces the risk of stroke and is used in the treatment of venous thromboembolism. It is a complex therapy that requires frequent monitoring, dose adjustment and the ability to follow instructions very closely. Numeracy effects compliance with such complex care (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004).

Numeracy is important to understanding risk. However, there is evidence suggesting that transmission of information from providers may cause more problems that lack of numeracy(Black, 1995). Framing effects, poor presentation and changes in reference class can cause confusion. Natural frequency is easier to understand than relative risk (Gigerenzer, 2003). It is important to use multiple formats of information to reduce format of information framing effects (Epstein, Alper, & Quill, 2004; Wills & Holmes-Rovner, 2003).

Validity of utility measurement depends on numeracy. In studies of effect of numeracy on utility, the gold standard of utility measures are self reported or hypothetical opinions (Woloshin, Schwartz, Moncur, Gabriel, & Tosteson, 2001). Also, utility can't be accurately measured in everyone. Similarly, there is no gold standard for quality of life. Is it possible that people who aren't literate have a lower quality of life (Schwartz, McDowell, & Yueh, 2004)? Age, level of education, and measurement method can effect utility (Badia, Roset, & Herdman, 1999).

Furthermore, is numeracy a proxy for age, level of education and/or socio-economic status (Estrada et al., 2004; Gazamararian et al., 1999; Schwartz et al., 2004)? Also, computer literacy may have influenced results (Schwartz et al., 2004).

#### Measurement

Nine empirical articles were reviewed which included scales. Several scales were used: 3, 4, 6 or 7 or 17 questions.

L. Schwartz validated three item scale. Scores are 0,1,2 or 3. Schwartz, Woloshin and Shapira analyzed every score group, others using similar scales used simply a numerate (2 or 3 correct) or non-numerate (0 or 1 correct) (Schapira, Davids, McAuliffe, & Nattinger, 2004; Schwartz, Woloshin, Black, & Welch, 1997; Schwartz et al., 2004; Woloshin et al., 2001). Is there a difference between score groups in a three point scale?

The 4 item Short Test of Functional Health Literacy in Adults (S-TOFHLA) scale includes actual hospital forms and labeled Rx vials (Gazamararian et al., 1999). Scores are included with the literacy

section for scoring. Useful, reliable and valid compared to the Rapid Estimate of Adult Literacy in Medicine (REALM).

The six question Black scale included answers and relationship between answers (Black, 1995). Subjects were analyzed as either numerate or not. Estrada added three anticoagulation specific questions to the three item Schwartz scale. Scores were analyzed as 0, 1-2, 3-4, 5-6(Estrada et al., 2004).

Lipkus used the Schwartz scale and also a 7 item scale that framed questions within the context of health risks (Lipkus, Samsa, & Rimer, 2001).

The TOFHLA has a 17 item numeracy scale (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

#### **Stability**

There is no work in examining the stability of numeracy over time.

#### **Sensitivity**

There is no work citing a shame in regard to a lack of numeracy. Low numeracy, however, is quite common and the widespread lack of numeracy across populations may decrease the level of sensitivity compared to, for example, reading numeracy.

#### Variable: Individual or Family Plan

#### Definition

An individual health coverage plan covers a single person; a family plan includes a spouse and/or children.

#### Bottom Line

Moderate importance.

#### Evidence

Health plan choices differ depending on whether the consumer has an individual or family plan. In a 2004 study assessing the selection of consumer driven health plans, those with individual coverage were more likely to select these plans (Fowles et al., 2004). In a study of annual health plan choice for 159 employees of a mid-sized corporation in a major Midwest city, the greater selection of the comprehensive plan by families reporting slightly lower family health status might indicate a greater focus on protection of relationships or provision of more choice when selecting for a family plan (Risker, 2000). The author noted the consistency with Juba, Lave and Shaddy, 1980, which argued that families well integrated into the health care community are reluctant to change health plans. Risker also found that the opinion of family members was the most influential factor to change of health plans. This being more true for men than women, but probably reflecting the greater coverage of family members by men in this study (men more often chose employee and children or family while women requested employee or employee and spouse coverage only). In another study, the opinion of family members and the uncertainty of dependants can cause one to switch health plans(McCormack, Garfinkel, Hibbard, Norton, & Bayen, 2001) and in a study by Robinson et al using admissions data and enrollment for period of 1981-1984, employees were shown to frequently switch health plans in anticipation of future maternity (Robinson JC, Gardner LB, Luft HS, 1993).

In a study based on performance data from a large employer that provided quality information (patient satisfaction and quality of care data) and assessed plan switching, choice seems to be driven more by policy type (family vs. individual ) than by age groupings e.g. younger families make choices more similar to older families than to younger individuals. Families tend to value quality, low price and smaller network combinations; older families frequently select the Point of Service (POS) option (higher premiums to retain partial coverage for services delivered by non-plan providers). Younger families are more price sensitive than older families but less than younger individuals (Beaulieu, 2002).

#### Measurement

The information was measured by self report through a mail survey and through employee profiles in human resources.

#### Stability

There is no data on the stability of this variable.

#### Sensitivity

There is no data on the sensitivity of this variable.

### Variable: Health System Utilization

#### Definition

Refers to the level of engagement with the health system and utilization of various medical services, including emergency room use, outpatient visits, and inpatient hospitalization. Also includes insurance status (insured vs. uninsured).

#### Bottom Line

Moderate importance. Most studies use health care utilization (HCU) as an outcome variable of various educational interventions. No studies were found that empirically compared those who utilized outpatient services, inpatient services, or ER services.

#### Evidence

Mailing an educational booklet about back pain did not reduce HCU although the study had several limitations(Hazard, 2000). Patients who participated in a Chronic Disease Self-Management Program made fewer ER visits compared to baseline at one year(Lorig, 2001) and two years(Lorig, 2001) and fewer physician visits. An educational program for patients with COPD resulted in a non-significant but small to medium effect size for reduced HCU (Devine, 1996). A 6-month "cluster visit" educational program for patients with diabetes significantly decreased inpatient and outpatient HCU(Sadur, 1999). A health education program tailored to older women (>60 year of age) reduced the number of inpatient stays and inpatient costs compared to the control group, but there was no significant change in ER utilization (Murray, 2000). In summary, health care education appears to reduce health care utilization.

Studies assessing health plan choice looking at health status often include medical services utilization as a component of health status and some assessed anticipated utilization in the upcoming year. For example, Fowles et al, 2004 included items related to health care utilization including treatment for chronic condition, hospitalization, visits and anticipated medical care. Atherly, Dowd and Feldman, 1999, used self reported health status and a score for the number of chronic illnesses present and Strombom, et al., 2002 utilized hospital discharge and cancer registry data as measures of chronic illness. These factors impacted information sought e.g. benefits and price sensitivity and impacted choice. The chronically ill are more interested in particular benefits, size of specialist network for example.

Poor health status and greater utilization of health services in the previous year have been related to the decision to switch health plans(Oetjen et al., 2003) (Hibbard et al 1997, Klinkman 1991 and Sofaer et al 1992 – cited in Oetjen, Fottler and Unruh, 2003).

Anticipated medical service utilization also plays a role in choice of health plans. In a study by Robinson et al using admissions data and enrollment for period of 1981-1984, they found that employees frequently switch health plans in anticipation of future maternity needs but not so much for other services. (Robinson JC, Gardner LB, Luft HS, 1993)

In fact, Lubalin, et al 1999 noted that because of the focus of consumers on services that they need, it is important to assist them in anticipating future medical service needs as they make their health plan choices.

#### Measurement

The Healthcare Cost and Utilization Project provides multi-state population based data on insured and uninsured patients, but clinical detail (e.g., disease stage) is not provided (Steiner, 2002). One study utilized hospital discharge and cancer registry data (Strombom et al., 2002) but most used self report of visits, hospitalization, etc..

### **Stability**

With health education, HCU may decrease and switch from ER to outpatient visits.

### Sensitivity

Patient who utilize the ER may be more likely to be uninsured and to have limited health literacy.

# Variable: Satisfaction with Plan or Provider

#### Definition

The level of satisfaction one has with current health coverage plan or physician.

#### Bottom Line

Important to include.

Satisfaction with plan and with physician are factors in choice of another plan.

- Plan performance in specific aspects of care needed.
- Satisfaction with providers is important especially, patient physician interaction and relationship.

#### Evidence

Based on a study of consumer satisfaction surveys and information valued when choosing a health plan several distinct factors emerge (Short et al., 2002). Plan performance is important in the services and benefits the consumer uses. Valuing of consumer satisfaction extends to information seeking when a consumer considers switching health plans. Consumers value surveys of consumer satisfaction surveys over professional performance measures (Booske, Sainfort, & Hundt, 1999), and value most highly the opinions of consumer's who are most like themselves demographically and in terms of the conditions they have and the services they use (Knutson et al., 1996; Lubalin & Harris-Kojetin, 1999).

In the past, confusion about the role of the plan itself caused many consumers to consider satisfaction and quality of care purely a function of the physician (Jewett & Hibbard, 1996; Lubalin & Harris-Kojetin, 1999). The patient-physician interaction and relationship is valued as one of the most important factors related to overall satisfaction with a health care plan (Lubalin & Harris-Kojetin, 1999; Short et al., 2002). In fact, there is a reluctance to change physician when one perceives a good relationship.

There is also a pattern of utility depending on whether the consumer is publicly or privately insured. Private insured care much more about keeping their own provider or finding a doctor they are happy with, as well as costs. However, the most frequently cited characteristic of interest for the Medicare/Medicaid enrollees was a doctor who communicates well, and several factors related to access to providers as well as hospitals and specialists, including the convenience of location (Short et al., 2002).

#### Measurement

The referenced studies used self-reported measures of satisfaction.

#### **Stability**

Satisfaction is likely to change as the related factors of access, communication and price change.

#### **Sensitivity**

There is no evidence of shame involved in satisfaction.

# Variable: Plan Tenure

#### Definition

The length of time enrolled in a health insurance plan. Frequently related to the length of time in current job, including whether the consumer is a new hire or current employee.

#### Bottom Line

Important to include.

#### Evidence

The primary impact of plan tenure on health insurance choice is the inertia effect. When one is in a health plan for a few years, he/she is less likely to switch to a new plan, this was seen by Beaulieu, 2002 to be the main driver of choice and by Srombom, et al, 2002 to be true even when price increased and when new options were available (Beaulieu, 2002; Stromborn et al., 2002). Researchers note that this may in part be due to a 'cost' to switching, including the need to learn a new system, reluctance to change a relationship with the current provider as well as confidence with the choice. Some evidence suggests that while this inertia effect may not effect the seeking of information it still may affect the willingness to change health plans. For example, Medicare benefactors used plan information to confirm a choice already made and those with more plan tenure were less likely to use the information to switch (McCormack et al., 2001). Studies suggest that it is more effective to target new enrollees with health plan choice information (McCormack et al., 2001; McLaughlin, 1999; Oetjen et al., 2003; Strombom et al., 2002). Plan tenure is also related to job tenure; many studies use job tenure or comparisons of new hires with tenured employees when assessing health plan changes and see a similar inertia effect (Beaulieu, 2002; McCormack et al., 2001; Strombom et al., 2002). Job tenure, therefore, may be a proxy for plan tenure. Also, it may also be important to consider that someone with long plan tenure may, through a job change, be driven out of 'status quo' and choose a new plan.

#### Measurement

The information was measured by self report through a mail survey (McCormack et al., 2001; McLaughlin, 1999), and administrative files (Oetjen et al., 2003).

#### **Stability**

There is no work citing stability in regard to plan or job tenure.

#### Sensitivity

There is no work citing sensitivity in regard to plan or job tenure.

# Variable: Risk Aversion

#### Definition

Risk aversion is the degree to which one chooses the less risky alternative.

#### Bottom Line

Important to include.

#### Evidence

Consumers who value health and health insurance will be less price sensitive. Such consumers will pay more for less constraints on care. Experts in academia are less likely to choose a managed care plan, possibly due to high values for health care cause them to choose the "blue ribbon" plans (McCormack et al., 2001).

Consumers may be over insuring and employees can be educated to bear more risk (Oetjen et al., 2003). Risk adverse individuals are less likely to change from a familiar plan (Strombom et al., 2002).

There is limited evidence regarding risk adversity and selection of a health care plan. According a review by Klemperer, cited in Strombom et al 2002, a consumer's willingness to switch health plans can be effected by uncertainty in the new plan options. Strombom states that, "... consumers will have better information on the quality of their current plan than on the quality of its competitors. This information asymmetry makes plan changes costly for risk-adverse individuals," (Klemperer, 1995).

In a study of 159 employees making their annual health plan choice the authors suggest that employees with higher education levels were willing to incur more risk in their choice to change health plans (Risker, 2000). This, they also noted, corroborates another study that found higher education levels increased likelihood of choosing an HMO with health status considerations offsetting this trend (Juba, Lave, & Shaddy, 1980.).

#### Measurement

No measure of risk aversion is available in the referenced literature.

#### **Stability**

Risk is noted as reason for different choices correlating with other factors such as age, income, education, individual versus a family plan.

#### Sensitivity

There is no data in regard to sensitivity of risk aversion.

### Variable: Health Information Seeking Preferences and Behaviors

#### Definition

Health Information Preferences include the communication channels that an individual prefers to use; the amount and type of information desired. Health Information Behaviors include the communication channels that an individual has used in the past, satisfaction with those channels, and satisfaction with the information obtained.

#### Bottom Line

Important to include.

#### Evidence

Health information seeking is driven by a need for information and the motivation to use a given medium. Available research tends to focus on specific diseases (i.e., new diagnosis of cancer), specific populations (i.e., underserved), and use of specific sources of health information (i.e., the internet). Differences emerge based on age, gender, ethnicity/race, education, socioeconomic status, and whether information seeking is driven by an immediate need. For example, demographic characteristics such as younger age, female gender, higher socioeconomic status, and being married have been shown in previous studies to be positive determinants of information seeking. Those less likely to seek information are the elderly.

There is convincing evidence that health information seeking has important implications for health outcomes. Patients who are well-informed tend to have a better sense of control, cope with uncertainty, follow their therapeutic plans and recover more quickly. Positive outcomes when preferences match physician behavior (Czaja, Manfredi, & Price, 2003). Available evidence indicates that almost all patients want to be fully informed by their physician about the various aspects of their disease and their treatment, preferring all information, across levels of acuity (Davis, Hoffman, & Hsu, 1999; Ziegler, Mosier, Buenaver, & Okuyemi, 2001). Previous adverse effects of medication and health consciousness, however, are association with increased information seeking (Dutta-Bergman, 2005; Ziegler et al., 2001).

Although the expressed desire for information is uniformly high, patients vary widely in the type and amount of information-seeking behavior they actually exhibit. Preferences often do not match behavior (Auerbach, 2001; Czaja et al., 2003; Ziegler et al., 2001). Studies have shown gender differences. In a study of Rheumatoid arthritis patients, lack of a Disease-modifying anti-rheumatic drug (DMARD) was associated with a stronger preference for information in women (Fraenkel, Bogardus, Concato, & Felson, 2001). However, in a later study, increasing number of DMARDS were associated with increased need for information in men (Neame et al., 2005). The same study listed three additional studies that do not associate need for information with health status or behavior. Multiple studies failed to find an association of health information seeking with health status or health behaviors (Elf & Wikblad, 2001; Ende et al., 1989; Krupat, Fancey, & Cleary, 2000; Stavri, 2001). Rees concluded that information seeking is individualistic (Rees, 2001).

There is extensive information regarding Internet health seeking. The *Pew Internet and American Life Project's* most recent update (2003) reports that while the Internet population stabilized during 2001-2002 at 60% of the population, 80% of users sought health information. Women and those who are better educated are the biggest seekers of health information. Specific disease and treatment information are the most desired topics, followed by information on drugs, diet, and exercise. Health

consciousness (healthy activities and beliefs, such as not smoking, eating a healthy diet, exercise) has been shown to be positively correlated with information-seeking on the internet suggesting that the underlying motivation is a specific health issue that is likely to draw the consumer to use the media. This match between content-based motivation and internet content sought is not surprising because of the user-driven nature of the internet. Internet experience is a strong predictor of future use. Consumers who sought out medical news on the internet and consumers who sought out information about drugs and medication were more health information oriented.

Selection of Health Care Plans:

Consumers show strong preferences for the type of information that they want for their selection of health plans and reliance on each of these varies depending on characteristics of the consumer. The information that is important to consumers includes:

- <u>Price</u>: Evidence suggests that price is the most important variable for most if not all consumers. Price includes: routine visit cost, coverage of wellness visit and monthly premium (Booske et al., 1999; Buchmueller & Feldstein, 1996; Gates, McDaniel, & Braunsberger, 2000; McLaughlin, 1999; Schur & Berk, 1998; Tumlinson, Bottigheimer, Mahoney, Stone, & Hendricks, 1997). A change in price can encourage voluntary movement. In 1984, an increase of \$5 per month increased switching between plans. In 1994, it was \$10 a month. One study found that women are more price sensitive, tolerating between \$25-\$50 premium increase, while men tolerated a premium increase of \$50 (Risker, 2000). There are sub-categories of information that are also highly variable among different consumers. For example, cost may be important in one category, such as the co-pay for a primary care physician, specialist, or prescription drug (Atherly et al., 2004) (and unpublished reference therein Buntin, 2000). Consumer interest in co-pays and benefits is highly variable depending on health status, chronic conditions, health care utilization (Atherly et al., 2004; Gates et al., 2000).
- <u>Benefits:</u> After cost, benefits and coverage is the most important factor for most consumers, including coverage limits, prescription coverage, mental health, long term care (Buchmueller & Feldstein, 1996; Gates et al., 2000; McLaughlin, 1999; Schur & Berk, 1998; Tumlinson et al., 1997). Consumers often choose a health plan based on its benefits. One study found that healthy consumers choose plans with dental benefits, chronically ill favor plans with prescription drug benefits and those with a chronic illness will choose plans with benefits that are pertinent to their condition such as vision benefits for diabetics (Atherly et al., 2004; Feldman et al., 2003). In addition, when assessing health plans they focus on services consumers use and value consumer satisfaction information about those services and benefits from consumers like them (i.e. conditions, health status, demographics) (Lubalin & Harris-Kojetin, 1999).
- <u>Provider Panel:</u> Much of what consumers consider important when selecting a health plan is based on provider interaction, including both physician and specialist network and inclusion of their current physician (Beaulieu, 2002; Buchmueller & Feldstein, 1996; Gates et al., 2000; McLaughlin, 1999; Schur & Berk, 1998). Access to physician and specialist care and physician relationship are important factors for consumers (Chernew & Scanlon, 1998). In fact, Lubalin, et al. found that access was the most important performance factor for health plan selection for older and Medicare/Medicaid beneficiaries and that factors related to physician relationship were important for those insured privately and publicly (Lubalin & Harris-Kojetin, 1999). Satisfaction with one's primary care physician can explain much of overall plan satisfaction (Willams, O'Connor, & Shewchuk, 2003).

- Ouality: There is some debate over the importance of qualitative information (McLaughlin, 1999; Schauffler & Mordavsky, 2001; Tumlinson et al., 1997). Many employees with a health plan choice do not understand the role of the health plan in quality of care and simply assume that their employer would not offer a plan of lower quality (Knutson et al., 1996; Lubalin & Harris-Kojetin, 1999). Studies suggest that consumers are interested in the quality of the insurance plan and the source of that information is important, including variables related to access and physician relationship (Lubalin & Harris-Kojetin, 1999). They place highest value on consumer satisfaction information, (Jewett & Hibbard, 1996) especially from consumers like them with respect to health status and conditions. In fact, they value consumer satisfaction surveys as much if not more than information from professional organizations (Booske et al., 1999; Lubalin & Harris-Kojetin, 1999). Some studies suggest that professional quality measures would be valued by consumers if these measures were clearly defined. (Jewett & Hibbard, 1996; Lubalin & Harris-Kojetin, 1999). It is important to note that although consumers often state the importance of having this quality information, there is evidence suggesting that first they compare cost and coverage (Booske et al., 1999) and it does not impact the actual selection of a plan (Knutson et al., 1996; Short et al., 2002). Consumers are interested in comparison data about health care plans and are disappointed with what is available regarding satisfaction.
- <u>Personal sources of information</u>: Interpersonal communication is important when making a health plan choice (Risker, 2000). Consumers with a health plan choice are skeptical and trust their doctor, friends and family (Gibbs, Sangl, & Burrus, 1996), preferring information from, "people like me" (Lubalin & Harris-Kojetin, 1999; Robinson & Brodie, 1997; Schauffler & Mordavsky, 2001). In one study of health plan choice, the opinion of a family member was the most important factor in plan selection (Risker, 2000). However, it has been suggested that fair to poor health status may reduce reliance on family and friends for this information (Harris, 2003). Furthermore, consumers find survey-based data more useful than records-based data probably due to ease of understanding. In fact in one study it was the most important factor after advice from doctor, family and friends (Lubalin & Harris-Kojetin, 1999).
- <u>Insurance type:</u> There are distinctions in what factors are important when selecting a health plan between those insured publicly vs. privately. Information about the physician and specialist network is more important than price information for Medicare patients (Short et al., 2002). One study assessing quality information suggested that the type and amount of information sought depended upon the insurance type (e.g., in a focus group assessing quality indicators, the privately insured asked more questions than the publicly insured). Furthermore, in terms of educational focus it appears that the publicly insured consumer is more vulnerable to misinformation than the privately insured consumer (Jewett & Hibbard, 1996). When reviewing quality data, publicly insured consumers prefer plans with more favorable scores for providers who communicate well, ease of access, time with patient, getting a good specialist. Privately insured consumers prefer plans with more favorable scores for keeping your doctor, finding the right doctor and low costs or premiums (Short et al., 2002).
- <u>Considering a Choice of Health Plan:</u> Oetjen found that consumers who are considering a change of health plan, are more likely to use health plan choice information (Oetjen et al., 2003).

# Measurement

Validated instruments to measure health information needs and health information seeking are lacking. Data are generally collected using questionnaires designed for specific studies. Some are based on theoretical models of information seeking. For example, the PRECEDE Model of information seeking has been used in a number of studies to examine factors that affect information

seeking (Kreuter & Holt, 2001). The model includes predisposing factors, enabling factors, and reinforcing variables. Enabling factors are the beliefs and attitudes that enhance the likelihood that individuals will seek information (i.e., cancer fear, family history of cancer, privacy issues, cancer misinformation, and coping style). Enabling factors also include resources that facilitate access to and use of services (i.e., social network variables and variables measuring familiarity with the medical system, disease and its treatment; preferences for receiving health information, religious beliefs, economic factors, and mistrust of the medical community). Reinforcing factors include both the encouragement and the disincentives that patients receive from health professionals or others for engaging in certain behaviors. These would include positive attitudes towards involvement in one's medical care and personal experiences in medical settings.

The Autonomy Preference Index includes preference for information seeking (Ende et al., 1989). This 8 item scale is expressed on a scale from 0 to 100 with 0 referring to a strong disagreement with statements, 100 referring to strong agreement and 50 to a neutral reaction. Other scales include the Krantz Health Opinions Survey-Information Scale, Miller Behavioral Style Scale, Beisecker Desire for Information Scale and from Davis, a visual analog scale.

#### **Stability**

There is little work in examining the stability of health information seeking over time. Information seeking behaviors change during disease trajectory (Echlin & Rees, 2002).

#### Sensitivity

Studies note increased concerns for sensitivity of information and privacy concerns among certain populations (i.e., African-American men). The responses of over 76,000 women to a survey question (Dye, Wojtowycz, Applegate, & Aubry, 2002) suggest that their willingness to share data is not a random event. Differences were observed by socio-demographic and attitudinal characteristics that may reflect larger cultural factors. Age, race, insurance coverage, and education appear to be factors. For example, women over the age of 40 were nearly 2 ½ times more likely to refuse to share information and, women with higher educational levels were more likely to refuse compared with women with a high school education only. Seeking health information has been reported to be sensitive in certain cultural groups. For example, Matthews et al. (Matthews, Sellergren, Manfredi, & Williams, 2002) note that African-Americans traditionally have been less active seekers of information regarding their illness than members of other ethnic groups (Freimuth, Stein, and Kean, 1989).

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