Health Information and Decision-making Preferences in the Internet Age: A Pilot Study Using the Health Information Wants (HIW) Questionnaire

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ABSTRACT
Recent paradigm shift in health care calls for more attention to patient preferences. The Health Information Wants (HIW) Questionnaire measures patients’ preferences (desires) for health information and participation in decision-making. It has parallel items in seven corresponding areas of information and decision-making (diagnosis, treatment, laboratory test, self-care, complementary and alternative medicine, psychosocial, and health care provider). A pilot study was conducted to generate preliminary data about the psychometric property of this instrument, the relationships between information and decision-making preferences in each of the seven areas, and the relationships among Internet use, age, and preferences for each type of health information and decision-making. The results show that the HIW Questionnaire has strong reliability and validity. After controlling for gender, education, perception of severity, and health, the overall preferences for health information and decision-making were positively correlated. Multilevel modeling analysis results showed that age was negatively related to the overall preference ratings. The differences in decision-making preference ratings between young and older adults were greater than those in information preference ratings. Internet use frequency was not significantly related to preference ratings. The relationships examined varied across the seven subscales (e.g., on the diagnosis subscale, age was positively associated with diagnostic decision-making preferences). These findings have implications for a better understanding of patient preferences, patient-provider relationships, and the quality of health care.

Categories and Subject Descriptors
I.3 [Computer Applications]: Life and Medical Sciences – health.

General Terms
Measurement, Theory.

Keywords
Health information, decision-making, health information wants (HIW), patient preferences, instrument development.

1. INTRODUCTION
During the past few decades, the dominant decision-making model in health care has been shifting from the paternalistic model (i.e., patients expected to be passive recipients of health care while doctors expected to make all the decisions) to the informed or shared decision-making model (i.e., patients expected to stay informed and be more active in their own health care decision-making) [1-5].

Developments in Internet technology facilitate this paradigm shift [6-8]. At the core of the medical professionalism is a distinctive competence, or the asymmetry of medical competence between the physician and the patient [9]. Two of the core attributes of this competence are cognitive, or knowledge and skills that professionals possess, and collegial, or self-monitoring and self-discipline to ensure the competence of members of the profession [9]. The Internet enables patients to challenge these two core attributes by creating unprecedented new opportunities to rich resources of both medical knowledge and knowledge about physicians’ credentials and styles [6-8].

Whether patients might actually take advantage of these new opportunities is a different matter. Recently, there has been much interest in preferences for health information (i.e., the interest in obtaining health information) and preferences for participation in decision-making (i.e., the interest in playing a role in making health-related decisions) [10]. These two types of preferences have been identified as the two dimensions of patient autonomy [11]; yet, they seem to be uncorrelated: there is ample evidence suggesting a discrepancy between preferences for health information and decision-making. On the one hand, patients generally have strong preference for having detailed health information. On the other hand, however, their desire for participation in decision-making is generally much less [see 12, for a review]. Research has identified several factors (e.g., the severity of condition, being in the role of a patient, cultural
norms, socio-demographic factors, and personality) as being predictive of the low level of decision-making preferences [see 13 for a review]. Yet, at least 80% of the variability between these two types of preferences still remains unexplained [10, 11, 14].

One factor that may have contributed to the reported low degree of preference for decision-making has not yet been examined; i.e., important types of decision-making were not measured previously. A comparison of commonly used instruments provides supporting evidence: while the types of health information are measured broadly including information about treatment, diagnosis, laboratory test, self care, and the psychosocial aspects [11, 15-21], the types of decision-making are measured narrowly – primarily (standard) treatment decision-making [11, 15, 16, 20, 22]. The psychosocial and diagnostic types of decision-making were completely absence from all five of the commonly used decision-making instruments [11, 15, 16, 20, 22]. Yet, it is long recognized that people want to have information about a stressful event (e.g., a new diagnosis) to make decisions about, for instance, how to control their anxiety [23-27]. Also, in the past few patients had access to information needed to make a diagnostic decision; thus, it might not be necessary previously to measure diagnostic decision-making. However, this may have to be changed: Internet research suggests that notable number of people has begun to make their own diagnostic decisions based the information they obtained online [28, 29]. Including these types of decision-making in the measurement may help address the previously reported low level of desire for decision-making.

2. POTENTIAL INTERNET EFFECTS

To our best knowledge, currently there is no validated instrument measuring online health information and decision-making preferences. There is, however, an observable trend: Internet research on health information and decision-making covers a broader range of the types of both health information and decision-making than previous research [28, 30-35]. A Kaiser study [36] reveals that, in addition to information about diagnosis and treatment, older Internet users also searched on the Internet information about nutrition, exercise or weight issues; Medicare and Medicaid; health policy; health providers; alternative treatments; and health insurance. A PEW study [37] measures not only treatment decision-making but also decisions regarding question-asking patterns when interacting with physicians, ability to cope with a condition, and ways of thinking about diet, exercise, or stress management. Other Internet studies measure explicitly diagnostic decision-making [28, 29].

This recent trend in the scope of measurements may well reflect the impact of the Internet on health care: in the past, patients might also desire to have information about, for instance, the credentials of a physician; however, there was no easy way for them to obtain such information. Thus, it was not common for patients to make informed decisions on their own regarding which provider to choose. The dramatic development of the Internet has made it possible to obtain such information with relative ease [38]. Now it is more common that patients make informed decisions about health care providers using the information they can obtain from sources like the Internet [31, 39].

Despite these changes, Internet research still cannot help fully explain the discrepancy between preferences for health information and decision-making. In the few existing studies that explicitly aimed to investigate the “reasons” or “motivations” for seeking health information online [39, 40], the reported reasons/motivations were mostly situational (e.g., an individual is interested in seeking health information about a specific health condition because he or she has recently been diagnosed with this health condition) or informational (e.g., simply to access more information about an illness) rather than decisional (which would be, for instance, to make decisions regarding treatment).

To date only a handful of Internet studies have examined health information and decision-making simultaneously. The results are quite mixed. Some find a positive correlation between online health information seeking and participation in decision-making [28, 37, 41]. Others fail to find a connection between these two variables [30, 42]. Several studies find that the majority of those who seek health information online conduct their online searches either unrelated to or after a visit to physician [33, 34, 42]. This suggests that seeking information online is likely not associated with preparation for participation in decision-making during a visit. More work needs to be done to better understand the relationships among Internet use and the overall preferences for information and decision-making and among Internet use and each type of information and decision-making preferences.

Research provides strong support suggesting that older adults are less likely than their younger counterparts to be interested in both health information and participation in decision-making [10, 43, 44]. There is evidence that age-related changes in cognition [45] and emotional processing and motivation [46] affect older adults' decision-making. Still, little is known about the relationship between younger and older adults’ preferences for health information and participation in decision-making, or how Internet use may (or may not) interact with these age-related changes to affect preferences. Our own exploratory research [13] on older Internet users’ and nonusers’ health information and decision-making preferences revealed an interesting absence of desire for participation in decision-making: These older adults rely primarily on medical professionals to make diagnostic and (standard) treatment decisions for them, and this reliance is not affected by their use (or non-use) of the Internet. This suggests that Internet use, while enabling new forms of participation in decision-making, has not changed older adults’ reliance on providers for these important types of decisions. Our finding is in line with those reported in other studies [36, 39], which suggests the generalizability of this finding to different older adult populations.

One likely reason is that, although the Internet can help to narrow the expertise gap between patients and providers, it can so only to a limited extent [47]. To take advantage of the new opportunities created by the Internet, individuals have to possess sufficient knowledge and skills that can enable them to do so. This can be difficult for older adults, who tend to have poor computer skills and often are unable to find relevant, high quality health information on the Internet [31, 48, 49]. Further research is necessary to better understand the interaction among Internet use, age, and preferences for information and decision-making.

3. THE HIW QUESTIONNAIRE

To address these gaps in the literature, it is important to first develop an instrument to measure both information and decision-
making preferences broadly and with parallel items in the corresponding areas. The HIW Questionnaire was developed for this purpose. The development entailed a multi-stage process that lasted for over two year. To date, this process has included five major stages. Stage 1 involved a grounded theory-driven, exploratory study [13] that identified the core concept of Health Information Wants (HIW), or “health information that one would like to have and use to make important health decisions that may or may not be directly related to diagnosis or standard treatment” [13, p. 514]. This concept explicitly situates information and decision-making preferences in relation to one another, which provides the basic structure for the HIW Questionnaire. The other major stages of the development process included: Stage 2, initial item development based on the literature and the exploratory study; Stage 3, content validity testing; Stage 4, cognitive testing; and Stage 5, a pilot study testing. Detailed descriptions of the first several stages will be reported elsewhere. In this paper we focus on Stage 5, reporting the results of the pilot study.

4. PILOT STUDY
In February-March 2010, the HIW Questionnaire was pilot tested with 43 individuals to generate preliminary data about the psychometric properties of the instrument and to begin to address the following research questions and hypotheses.

4.1 Research Questions (RQs) and Hypotheses (Hs)
Prior research suggests a lack of significant correlation between health information and decision-making preferences: a desire for information may not necessarily be associated with a desire for participation in decision-making. We argue that one possible reason lies in the differences in how these types of preferences are measured: in existing instruments, decision-making measures focus predominantly, if not exclusively, on treatment decision-making while information is measured more broadly: information measures include but are not limited to treatment information. Because the HIW Questionnaire was carefully designed to feature parallel items in each type of information and decision-making, we hypothesized that:

H1: There is a positive association between the overall preferences for health information and decision-making.

Prior research provides insufficient evidence with regard to the relationship between each type of information and decision-making preferences, because several types of preferences were not even measured in the commonly used instruments. The unique design of the HIW Questionnaire (covering a broad range of the types of information and decision-making preferences with parallel items in corresponding areas of the types of information and decision-making) enabled us to ask the following research question:

RQ2: What is the relationship between each type of preferences for health information and decision-making?

Prior research suggests that age is negatively associated with both information and decision-making preferences, more so with the decision-making than information preferences [10, 43, 44]. Thus, we hypothesized that:

H2a: There is a negative association between age and the overall preferences for both health information and decision-making.

H2b: There is a greater difference in the overall preference for decision-making than that for information between younger and older adults.

Prior research provides insufficient evidence regarding the relationship between age and each type of preferences for information and decision-making. Thus, we asked the following research question:

RQ2: What is the relationship between age and each type of preferences for information and decision-making?

Prior Internet research provides insufficient evidence regarding the relationship 1) between Internet use and the overall preferences for both health information and decision-making; and 2) between Internet use and each type of preferences for information and decision-making. As reviewed above, the handful of Internet studies that examined health information and decision-making simultaneously reported mixed results. These mixed results led us to ask the following research questions:

RQ3: What is the relationship between Internet use and the overall preferences for health information and decision-making?

RQ4: What is the relationship between Internet use and each type of preferences for health information and decision-making?

4.2 Study Design
4.2.1 Participants
A convenience sample of 43 individuals, including 22 undergraduate students in a variety of disciplines at a large state university and 21 older adults recruited from a public library computer class, participated in the pilot study. Participants’ demographic characteristics are summarized in Table 1 below.
Table 1. Demographic characteristics of pilot study participants (N = 43).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Young</th>
<th>Older</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimum</td>
<td>18</td>
<td>56</td>
<td>18</td>
</tr>
<tr>
<td>Maximum</td>
<td>25</td>
<td>84</td>
<td>84</td>
</tr>
<tr>
<td>Mean</td>
<td>20</td>
<td>70</td>
<td>44</td>
</tr>
<tr>
<td>SD</td>
<td>1.7</td>
<td>6.9</td>
<td>26</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>82%</td>
<td>81%</td>
<td>81%</td>
</tr>
<tr>
<td>Male</td>
<td>18%</td>
<td>19%</td>
<td>19%</td>
</tr>
<tr>
<td><strong>Marriage status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>5%</td>
<td>48%</td>
<td>26%</td>
</tr>
<tr>
<td>Single</td>
<td>96%</td>
<td>19%</td>
<td>58%</td>
</tr>
<tr>
<td>Widowed</td>
<td>0%</td>
<td>33%</td>
<td>16%</td>
</tr>
<tr>
<td><strong>Highest level of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>27%</td>
<td>24%</td>
<td>26%</td>
</tr>
<tr>
<td>Vocational training</td>
<td>0%</td>
<td>19%</td>
<td>9%</td>
</tr>
<tr>
<td>Some college/associate's degree</td>
<td>68%</td>
<td>24%</td>
<td>47%</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>5%</td>
<td>14%</td>
<td>9%</td>
</tr>
<tr>
<td>Master’s degree or other post-graduate training</td>
<td>0%</td>
<td>19%</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>9%</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>African American</td>
<td>91%</td>
<td>90%</td>
<td>91%</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>24%</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>$30,000-$39,999</td>
<td>43%</td>
<td>62%</td>
<td>52%</td>
</tr>
<tr>
<td>$40,000-$49,999</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>$50,000-$59,999</td>
<td>5%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>$60,000-$69,999</td>
<td>19%</td>
<td>19%</td>
<td>19%</td>
</tr>
<tr>
<td>$70,000-$99,999</td>
<td>0%</td>
<td>10%</td>
<td>5%</td>
</tr>
<tr>
<td><strong>English as primary language</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>82%</td>
<td>95%</td>
<td>88%</td>
</tr>
<tr>
<td>No</td>
<td>18%</td>
<td>5%</td>
<td>12%</td>
</tr>
</tbody>
</table>

*: Percentage was calculated based on valid responses.

4.2.2 Materials
The 40-item HIW Questionnaire, a self-administered instrument, was used in the pilot study. This instrument includes two main scales: the Information Preference Scale, and the Decision-making Preference Scale. These two scales each contains seven sub-scales with parallel items in the following information and decision-making areas: diagnosis (6 items); treatment (9 items); laboratory test (4 items); self-care (5 items); complementary and alternative medicine (CAM) (6 items); psychosocial (8 items); health care provider (2 items). In the Information Preference Scale, participants were asked to indicate their preferences for each type of information (e.g., information about how severe a health condition is) on a five-point Likert scale, in which response choices range from 1 (None) to 5 (All). In the Decision-making Preference Scale, participants were also asked to indicate their preferences for each type of health decision-making on a five-point Likert scale (e.g., decision regarding how severe a health condition is). Adapted from Ende et al. [11], response choices were: the doctor alone (1), mostly the doctor, the doctor and myself equally, mostly myself, and myself alone (5). Before completing these two main scales, participants were asked to first think about a specific health condition they had in the past or currently have, and continue thinking about this health condition while filling out the rest of the questionnaire. A portion of the HIW Questionnaire is shown in Tables 2-3 below.
Table 2. Excerpt of the Information Preference Scale of the HIW Questionnaire.

<table>
<thead>
<tr>
<th>How much information would you like to have?</th>
<th>None 1</th>
<th>A little 2</th>
<th>Some 3</th>
<th>Most 4</th>
<th>All 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Information about what areas should be covered in the medical appointment to help to diagnose this health condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Information about the stage of this health condition (e.g., how advanced it is, how far it has spread)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Information about how severe this health condition is</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The rest of the Information Preference Scale is skipped here due to space limit.

Table 3. Excerpt of the Decision-making Preference Scale of the HIW Questionnaire.

<table>
<thead>
<tr>
<th>Who do you think should make the decision?</th>
<th>The doctor alone</th>
<th>Mostly the doctor</th>
<th>The doctor and myself equally</th>
<th>Mostly myself</th>
<th>Myself alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Decision regarding what areas to cover in the medical appointment to help to diagnose this health condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Decision regarding what stage of this condition it is (e.g., how advanced it is, how far it has spread)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Decision regarding how severe this health condition is</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The rest of the Decision-making Preference Scale is skipped here due to space limit.

In addition to the 40 parallel items in the Information and Decision-making Scales, the instrument also included a brief demographic questionnaire, an item on Internet use frequency, items that measure the control variables (e.g., perception of severity of the health condition), and one global item in each scale (for the Information Preference Scale: How much information would you like to have about this condition? For the Decision-making Preference Scale: Who do you think should make the decision related to this specific health condition?). (Copies of the HIW Questionnaire are available upon request to the first author.)

4.2.3 Procedure
The instrument was completed in approximately 15-20 minutes by the undergraduate students and 25-35 minutes by older adults. Completion of the instrument took place in a university classroom or office for the undergraduate participants and a public library for the older participants. Prior to the data collection, all participants completed the informed consent form, approved by the Institutional Review Board of the authors’ University.

4.2.4 Statistical Analysis
The current data contained a hierarchical structure in which each person rated items in both the information preference dimension and the decision-making preference dimension. Dimension of preference ratings is a within-subject predictor, whereas age and Internet use frequency were both between-subject predictors. Because both age and Internet use frequency were measured as continuous variables, the traditional repeated-measure ANOVA is not appropriate to test their effects on preference ratings. Therefore, we used the multilevel modeling technique in the data analysis [50]. Dimension of preference (i.e., information preference versus decision-making preference) was the Level-1 predictor (within-subject level predictor) on preference ratings. It was coded as a dummy variable with information preference = “1” and decision-making preference = “0”. Age and Internet use frequency were Level-2 predictors (between-subject predictors) on the random intercept and slope of the Level-1 prediction. The interaction effect between age and dimension of preference and the interaction effect between Internet use frequency and dimension of preference were tested as the fixed effects on the Level-1 random slope. The main effects of gender, education, self-perception of the severity of the health condition, and self-reported health status were controlled at Level 2.

4.3 Results
4.3.1 Reliability
We used Cronbach’s Alpha (\( \alpha \)) coefficients [51], a measure of internal consistency, as an estimate of reliability. Cronbach’s alpha measures how well the items that reflect the same construct yield similar results. The Cronbach’s alphas were .98 and .96 for information and decision-making, respectively, which indicates that the items within each dimension were internally consistent and reliable. The Cronbach’s alphas for the subscales within the information preference dimension ranged from .89 to .98 with a mean of .95. The Cronbach’s alphas for the subscales within the
decision-making preference dimension ranged from .75 to .96 with a mean of .89. Therefore, all the subscales were reliable.

4.3.2 Convergent validity
The scale score of information preference was positively correlated with the global item measuring preference for information ($r = .45$, $p < .01$). The scale score of decision-making preference was also positively correlated with the global item measuring preference for decision-making ($r = .28$, $p < .05$). These significant correlations support the convergent validity of the two scales.

4.3.3 Testing Hypothesis 1
Our first hypothesis is that there is a positive association between the overall preferences for health information and decision-making. Partial correlation analysis showed that, after controlling for gender, education, perception of severity, and health, the overall preferences for health information and decision-making were positively correlated (partial $r = .44$, $p < .01$), thus supporting Hypothesis 1.

4.3.4 Answering Research Question 1
RQ1 asked: What is the relationship between each type of preferences for information and decision-making? Partial correlation analysis showed that, after controlling for gender, education, perception of severity, and health, there were variations across the subscales in the relationship between preferences for information and decision-making. For the subscales of diagnosis, laboratory test, CAM, and psychosocial, preferences for information and decision-making were not significantly correlated. However, preferences for information and decision-making were positively correlated for the subscales of treatment (partial $r = .35$, $p < .05$), self-care (partial $r = .37$, $p < .05$), and health care provider (partial $r = .34$, $p < .05$).

4.3.5 Testing Hypothesis 2
Results of multilevel modeling analysis showed that age was negatively related to the overall preference ratings ($\gamma = -.01$, SE = .00, $p < .01$). This result supported Hypothesis 2a and indicated that, overall, young adults preferred more health information and participation in decision-making than older adults. However, age positively predicted the random slope between preference dimension and the overall preference ratings ($\gamma = .01$, SE = .01, $p < .05$), demonstrating significant interaction effect. Specifically, as shown in Figure 1, the differences in decision-making preference ratings between young and older adults were greater than those in information preference ratings. Therefore, Hypothesis 2b was also supported.

4.3.6 Answering Research Question 2
RQ2 asked: What is the relationship between age and each type of preferences for information and decision-making? Multilevel modeling analysis showed that, for ratings on diagnosis, age positively predicted this type of decision-making preferences ($\gamma = -.02$, SE = .01, $p < .01$). Specifically, as shown in Figure 2, young adults preferred more information but less participation in decision-making by themselves than older adults about diagnosis.
4.3.7 Answering Research Question 3
RQ3 asked: What is the relationship between Internet use and the overall preferences for health information and decision-making? Partial correlation analysis results showed that Internet use frequency was not significantly related to preference for information or decision-making after controlling for gender, education, severity, and general health status. Multilevel modeling results also showed that Internet use frequency was not significantly related to preference ratings. The interaction between Internet use frequency and preference dimension was not significant. These preliminary data thus suggest that there was no correlation between Internet use and the overall preferences for health information and decision-making.

4.3.8 Answering Research Question 4
RQ4 asked: What is the relationship between Internet use and each type of preferences for health information and decision-making? Multilevel modeling analysis showed that Internet use frequency was negatively related to preference ratings for the subscale of diagnosis ($\gamma = -.13$, SE = .05, p < .01) and positively related to preference ratings for the subscale of CAM ($\gamma = .20$, SE = .06, p < .01) and psychosocial ($\gamma = .19$, SE = .07, p < .01). Internet use frequency was not significantly related to preference ratings for the other four subscales: treatment, laboratory test, self-care, and health care provider. These results indicated that individuals who used the Internet more frequently preferred more information and participation in decision-making about CAM and psychosocial condition however less information and participation in decision-making about diagnosis.

The interaction between Internet use frequency and preference dimension on preference ratings was not significant for the subscales of treatment, laboratory test, self-care, and health care provider. However, Internet use frequency positively predicted the random slope between preference dimension and the preference ratings regarding diagnosis ($\gamma = .22$, SE = .09, p < .05). Individuals who used the Internet more frequently preferred more information but less participation in decision-making about diagnosis (Figure 5). In addition, Internet use frequency negatively predicted the random slope between preference dimension and the preference ratings for the subscales of CAM ($\gamma = -.37$, SE = .10, p < .01) and psychosocial ($\gamma = -.29$, SE = .13, p < .05). Individuals who used the Internet more frequently preferred less information but more participation in decision-making about CAM and the psychosocial aspects (Figures 6 and 7).
4.4 Discussion

Preferences for health information and participation in decision-making are the two dimensions of patient autonomy [11]. Prior research suggests that these two dimensions are not correlated: while individuals generally have a strong desire for having information, they may not necessarily want to participate in decision-making [12]. One possible reason for this discrepancy is that information and decision-making preferences are measured differently in prior studies. While measurements for decision-making typically focus (predominantly if not exclusively) on treatment decision-making, measurements for information usually focus on a broader range of the types of information – and even more so in Internet studies. The HIW framework [13], by identifying a broader range of the types of decision-making that each corresponds with one type of information, sheds new light on the widely reported discrepancy between preferences for information and decision-making.

Building onto the HIW framework, the HIW Questionnaire was developed to help test the relationships between preferences for information and decision-making. Unlike prior instruments, the HIW Questionnaire features parallel constructs and items in a broad range of information and decision-making preferences. Our pilot study provides preliminary evidence for the strong reliability and validity of the HIW Questionnaire. It also provides preliminary support for the hypotheses. The findings suggest that there is a positive association between the overall preferences for health information and decision-making, thus supporting Hypothesis 1.

Prior research shows that age is negatively associated with both information and decision-making preferences, and that the effect of age is greater in the decision-making than information dimension [10, 43, 44]. Our pilot study findings are in line with prior research in this regard: compared with younger adults, overall, older adults preferred less information and participation in decision-making. Further, the differences in decision-making preference ratings between younger and older adults were greater than those in information preference ratings. Hypotheses 2a and 2b were also supported.

Different from prior instruments, the unique design of the HIW Questionnaire (with parallel constructs and items in each construct in the information and decision-making dimensions) enabled us to look deeper into the relationships between the constructs in the two preference dimensions. The findings reveal interesting variations across the subscales in the relationship between preferences for information decision-making.

First, while preferences for treatment, self-care, and health care provider information were positively correlated with preferences for treatment, self-care, and health care provider decision-making, respectively, preferences for diagnosis, laboratory test, CAM, and psychosocial information were not significantly correlated with their counterparts in decision-making. One possible reason is that there may be cross associations among these types of preferences: that is, there may not be a precise one-to-one correlation between each type of information and decision-making preferences. Rather, multiple types of information preferences may be correlated with one type of decision-making preferences. For instance, preference for diagnosis information might not be correlated with preference for diagnosis decision-making but rather be correlated with preference for treatment decision-making. Perhaps patients want diagnostic information not because they want to use this information to directly make a diagnostic decision; rather, they want diagnostic information only because they want to use it to make decisions about, for instance, how to monitor the treatment decisions made by health care providers, and thus subtly, to participate in their own treatment decision-making. This would be in line with the findings of our exploratory study [13]. Due to the small sample size of this pilot study, we were unable to explore these potential cross correlations. This aspect will be addressed in our future research.

Second, while overall age is negatively associated with both information and decision-making preferences, for the diagnosis subscale of the Decision-making Scale, age was positively related to this type of decision-making preferences (and for the diagnosis subscale of the Information Scale, negatively related to this type of information preferences). This suggests that, older adults prefer more diagnostic decision-making while at the same time less diagnostic information than their younger counterparts. One possible reason might be that, as part of the aging process, people become more experienced with and knowledgeable about health conditions; subsequently, older adults may no longer be as interested as their younger counterparts in having information about these health conditions. For this same reason, older adults might also be more confident than their younger counterparts in making diagnostic decisions. Interestingly, the exact opposite occurred when it comes to the CAM and psychosocial dimensions: older adults preferred more information but less participation in decision-making than young adults on these two subscales. One possible reason may also be associated with the aging process: older adults generally suffer from more health conditions than their younger counterparts and thus are more interested in having CAM and psychosocial information. This same reason might also explain why older adults are less interested in participating in CAM and psychosocial decision-making; prior research suggests that, as the severity of health conditions increases, patients’ preference for participation in decision-making decreases [11]. These findings and possible reasons will be carefully explored in our future research.

Prior research found mixed results regarding the relationship between Internet use and preferences for health information and participation in decision-making. While some find that health information seeking on the Internet is positively associated with participation in decision-making [28, 37, 41], others fail to find connections between these two variables [30, 33, 34, 42]. Our pilot study did not find significant correlation between Internet use and the overall preferences for health information and decision-making. These findings are in line with prior studies that did not find correlation between these variables [30, 33, 34, 42]. Interestingly, the findings of the relationships between Internet use frequency and each type of the information and decision-making preferences replicate those between age and these preferences, suggesting that Internet use frequency might be a proxy of age when it comes to the relationships between age and each type of information and decision-making preferences.

4.5 Limitations

The current study has limitations. Since this was a pilot study, the results were derived from a small convenience sample. The participants were predominately African American (90%) and female (80%). Caution should be taken in generalizing the
findings to males and non-African Americans. In addition, the sample consists of two groups – undergraduates 18-25 years and older adults 56-84 years of age. Additional research should address the middle ages 26-55 to determine whether these results would be replicated. The older group had some familiarity with computers; it would be helpful to examine older adults with less familiarity. Internet use was measured by asking “How often do you use the Internet?” While this item is a good measure of Internet use frequency, it cannot tell us what activities participants do online, which may or may not be associated with accessing health information in preparation for making a decision. In future research, it will be necessary to add more relevant Internet use measures.

5. MOVING FORWARD

The HIW Questionnaire was developed to measure a broad range of preferences for health information and participation in health decision-making. Through the deliberate use of parallel items in the information and decision-making subscales, this instrument can be used to help better reveal the relationships between the various types of information and decision-making preferences. It can also help better understand the relationships between age, Internet use, and preferences for health information and participation in decision-making. Our pilot study provides preliminary evidence for the strong reliability and validity of the instrument. Multilevel modeling analyses have already begun to reveal interesting phenomena that were previously undetected (e.g., while overall age is negatively associated with both information and decision-making preferences, on the diagnosis subscale, age is positively associated with this type of decision-making preferences).

To fully investigate these phenomena, we are currently testing the HIW Questionnaire with a larger sample and expect to report the findings in fall 2010. With a larger sample, we will be able to conduct more analyses to investigate deeper: e.g., is preference for diagnosis information correlated with preference for psychosocial and/or other types of decision-making? Might multiple types of information preference be correlated with one type of decision-making preference? Perhaps patients want diagnostic information not because they want to use that information to make diagnostic decisions but instead to use it to make other types of decisions?

As a useful tool for understanding patients’ preferences, the HIW Questionnaire has the potential to help improve patient-provider relationships and the quality of health care. If our further research could provide convincing evidence that decision-making is a spectrum that includes not only treatment but also other types of decision-making (that were previously understudied), and that a desire for different types of health information is associated with a desire for different types of decision-making, then, health care professionals and researchers would need to adjust our mindset and practice dramatically in order to better accommodate patients’ (strong) desire for participation in a broad range of decision-making. This would likely lead to improved patient-provider relationships and quality of care.

6. REFERENCES


