The Control Preferences Scale
Lesley F. Degner, Jeff A. Sloan, and Peri Venkatesh

L'échelle d'identification des préférences (ÉIP) a été créée dans le but d'évaluer un concept issu d'une théorie empirique sur la manière dont les décisions de traitement sont prises chez les personnes atteintes de maladies graves. Le concept d'identification des préférences est défini comme étant « le degré de contrôle qu'un individu désire exercer en ce qui a trait aux décisions prises concernant le traitement médical ». L'ÉIP fait usage de cinq fiches qui illustrent différents rôles dans la prise de décision de traitement. Ces fiches contiennent un énoncé ainsi qu'un dessin humoristique, et les rôles présentés couvrent une gamme de scénarios, allant d'une décision de traitement prise uniquement par la personne jusqu'à une décision prise uniquement par le médecin, en passant par un scénario où la décision est prise conjointement par le patient et le médecin. En utilisant l'ÉIP, les sujets effectuent une série de comparaisons par paires dans le but d'établir l'ultime degré de préférence face aux cinq fiches. Ces degrés sont analysés à l'aide de la théorie du déploiement afin de déterminer la distribution des préférences auprès de différentes populations et l'effet des covariables sur les préférences des consommateurs. L'échelle a été testée chez de populations variées, lesquelles couvraient un bassin allant du public général à des groupes extrêmement stressés. L'ÉIP s'est avérée être une mesure de préférence de rôles qui est cliniquement pertinente, d'application facile, valable et fiable en ce qui a trait à la prise de décision en matière de soins de santé.

The Control Preferences Scale (CPS) was developed to measure a construct that emerged from a grounded theory of how treatment decisions are made among people with life-threatening illnesses. The control preferences construct is defined as “the degree of control an individual wants to assume when decisions are being made about medical treatment.” The CPS consists of five cards that each portrays a different role in treatment decision-making using a statement and a cartoon. These roles range from the individual making the treatment decisions, through the individual making the decisions jointly with the physician, to the physician making the decisions. The CPS involves subjects in making a series of paired comparisons to provide their total preference order over the five cards. These preference orders are analyzed using unfolding theory to determine the distribution of preferences in different populations and the effect of covariates on consumer preferences. The scale has been tested in a variety of populations, ranging from the general public to highly stressed groups. The CPS has proven to be a clinically relevant, easily administered, valid, and reliable measure of preferred roles in health-care decision-making.

Interest in the consumer’s potential role in health care has intensified as new perspectives emerge in medicine. The availability of treatment options with equivalent benefits in terms of survival have led to sug-

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gestions that it should be the consumer's preferences that guide final selection of treatment (Ganz, 1992). Similarly, shrinking resources in health care have led to the realization that when patients select their own treatment they are likely to adopt a more conservative approach to treatment than would their physicians (Wennberg, 1990). Concern over the degree of control over treatment decisions that people are currently able to assume, as well as speculation about the degree of control they actually want, have intensified as a result of empirical evidence that individuals who exercise control over decisions regarding their medical treatment have better outcomes (Fallowfield, Hall, Maguire, & Baum, 1990; Greenfield, Kaplan, & Ware, 1985; Morris & Royle, 1988).

One of the greatest challenges facing investigators is how to measure the degree of control that consumers of health care actually want. This measurement objective has to be realized before variations in decisional preferences among members of different disease/treatment groups or users in different health-care settings can be described. Accurate measurement of consumer preferences also provides the basis for examining the relationship between assuming decisional control and health-care outcome (Wallston et al., 1991).

This paper will describe the development of the control preferences scale (CPS), a measure designed to elicit consumer preferences regarding participation in health-care decisions. The CPS consists of five cards portraying five different roles consumers could assume in treatment decision-making. Each role is described by a statement and a cartoon (see Figure 1). Subjects make paired comparisons of a series of subsets of two of the five cards to yield their total preference order for the roles, ranging from most to least preferred. These preference orders are analyzed using unfolding theory to yield estimates of the degree of control that different populations desire in the context of treatment decision-making.

This paper will describe the emergence of the control preferences construct and the development of the control preferences scale, as well as basic information about the underlying measurement model. Practical information on how to use the scale, including testing, scoring, and data analytic procedures, will be provided, so that investigators will be equipped to use the measure in a variety of health-care applications. The CPS is a clinically relevant, easily administered, valid, and reliable measure of preferred roles in health-care decision-making.
**Figure 1  The Control Preferences Card Set**

<table>
<thead>
<tr>
<th>Active Role</th>
<th>Passive Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. I prefer to make the decision about which treatment I will receive.</td>
<td>E. I prefer to leave all decisions regarding treatment to my doctor.</td>
</tr>
<tr>
<td>B. I prefer to make the final decision about my treatment after seriously</td>
<td>D. I prefer that my doctor makes the final decision about which treatment</td>
</tr>
<tr>
<td>considering my doctor’s opinion.</td>
<td>will be used, but seriously considers my opinion.</td>
</tr>
</tbody>
</table>

**Collaborative Role**

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

The cartoon is one of five that represent different roles in decision-making. This one represents the collaborative role.

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**Emergence of the Control Preferences Construct**

The CPS has been two decades in development, beginning with a solid foundation in descriptive theory. The validity of the CPS derives from its grounding in the empirical world of health care. Between 1974 and 1978, data were collected in an extensive qualitative study designed to answer the general question “What happens when treatment decisions are made for patients with life-threatening illnesses?” (Degner & Beaton, 1987). The thesis of that study was that treatment decision-making took place within a social context, and as a result was influenced by that context, as opposed to being solely the product of the patient’s medical condition and available treatments.

While several factors influenced the way in which treatment decisions were made, the central factor appeared to be “control over the design of treatment,” or who actually selected the treatment that the patient received. Four patterns of decision-making were identified and described: provider-controlled, patient-controlled, family-controlled, and jointly controlled. This description (Degner & Beaton, 1987, pp. 27–37) provided the initial parameters for development of the control preferences construct. At the time that this study was conducted,
provider-controlled decision-making was dominant in health care, the other patterns being observed only rarely.

Description of the patterns of control led to the question “Do patients have preferences about the degree of control they actually want to exercise in treatment decision-making?” Informal participant observation at the University of Michigan Oncology Clinics and the Manitoba Cancer Treatment and Research Foundation Clinics during patients’ first referral visits provided evidence for the existence of such preferences. Some patients refused to become involved in selecting their own treatment, even when urged to do so by the physician, essentially saying, “It’s up to you, Doctor; you’re the expert.” Others indicated a need to discuss the available options with their physician, asking for the opportunity to go away and think about the discussion prior to making the final selection of treatment, with the physician, on the next visit. On rare occasions patients came obviously prepared, making it clear that it was their life and their body at stake and they would make their own treatment choices.

These observations led to formulation of the control preferences construct and the hypothesized psychological dimension that subsequently guided development of the measure (see Figure 2). The control preferences construct was defined as “the degree of control an individ-

![Figure 2 The Control Preferences Construct](image-url)
ual wants to assume when decisions are being made about medical treatment.” Patients were hypothesized to have differing preferences about keeping control over treatment decision-making, sharing control with their physician, or relinquishing control to their physician. That is, the individual preference of any particular patient would fall at a particular point along that psychological continuum.

**Distinction between Preference for Control and Preference for Information**

As described in the grounded theory of life-death decision-making that provided the basis for this work, desire for information is quite separate from degree of willingness to use this information in making choices (Degner & Beaton, 1987). Other authors have also emphasized the distinction between these constructs (Averill, 1973; Dennis, 1987; Krantz, Baum, & Wideman, 1980). As Sutherland, Llewellyn-Thomas, Lockwood, Trichler, and Till (1989) have noted, the need for information is probably related to the need to enhance psychological autonomy, and is not necessarily related to a desire to assume responsibility for treatment decisions. Put another way, people who want maximal information may have no interest in making choices about their medical care. The development of a separate measure of patients’ priorities for information is described elsewhere (Bilodeau & Degner, 1996; Davison, Degner, & Morgan, 1995; Degner et al., 1997).

**Development of the Control Preferences Scale**

**Selection of the Measurement Model**

The hypothesis that patients have preferences about their level of control in treatment decision-making guided selection of the measurement model, which is referred to as unfolding theory (Coombs, 1976). Unfolding theory is based on the premise that an individual’s preference corresponds to an ideal point on a continuum, and that this ideal point can be derived by presenting successive paired comparisons of stimuli that fall along the continuum. In the case of the CPS, the stimuli are the cards and the ideal point is represented by the order in which the subject places the cards, from most to least preferred (see Figure 1). Using Coombs’s terms, this order is referred to as an individual, or I, scale. For example, the individual who wanted the greatest degree of control in decision-making would put the cards in Figure 1 in the order ABCDE, while the person who wanted the least control would put them in the order EDCBA.
When series of I scales are unfolded, one can determine whether or not they are consistent with the existence of an underlying joint, or J, scale (see Figure 3). To offer a visual analogy, one can think of five beads (the stimuli or cards) fastened at different points on a string; the I scale is formed by picking up the string, or \( J \) scale, at some point (your ideal point) and folding it up. One then “unfolds” a whole series of these beaded strings (the preference orders) to determine whether the same \( J \) scale exists. When there are five stimuli (cards, in the case of the CPS), there are only 11 valid preference orders, or \( I \) scales, that would fall directly on the dimension (see Figure 4), out of a total possible 120 preference orders generated by every possible combination of five stimuli (cards). These valid preference orders are determined by the ordering of the stimuli (cards) and the midpoints between them (Coombs, 1976).

Unfolding analysis has proven to be a valid and reliable approach to instrument development, especially for unidimensional constructs (Bossuyt, 1990). This scaling approach is particularly useful in the measurement of abstract constructs. For example, Coombs applied unfolding theory to solve a problem his wife, a demographer, had met in measuring preferences for family size and composition among people in developing countries (Coombs, Coombs, & McClelland, 1975). The ease with which a measure based on unfolding theory could be applied in field settings, along with the opportunity for the first author to study with Dr. Coombs, provided the basis for selection of the measurement model.
Development of the Cards

The challenge for the investigator is to construct stimuli that fall on the hypothesized dimension, and that fall a "just noticeable difference" apart so that individuals can express their preferences while making minimal errors. The goal is to ensure that subjects can discriminate between adjacent stimuli. Construction of the stimuli for the CPS took place in two phases. In the first pilot test, five potential decisional roles were identified through participant observation and the participation of judges at the University of Michigan Oncology Clinics. For ease of administration of the measure, these roles were described in statements placed on five separate cards. The preliminary measure was then tested with a theoretical sample of 60 cancer patients, but one of the statements was found to be problematic and was subsequently dropped from the scale (Degner & Russell, 1988). This statement described the role in which the patient selected a physician who would administer the treatment that the patient had already selected. In retrospect, this role was identified because the statements were developed in an American clinic where patients assumed a very consumerist stance, while the pilot test was conducted in a Canadian clinic where patients tended to assume more passive roles in decision-making.

In the second phase, the statements were revised based on work by Strull, Lo, and Charles (1984) and pilot tested with 30 men who had testicular cancer. The second pilot test led to a revision of the statements and the addition of cartoons. Patients had difficulty understanding the concept of shared control; the addition of a cartoon helped them grasp this idea. Also, the literacy level of some patients was such that the research nurse had to read them the statements during testing; the cartoons provided these patients with a way to focus on the task.
Research Applications

Presentation Procedures

Administration of the CPS requires subjects to sort a series of cards through successive paired comparisons. The result of these comparisons consists of an ordered permutation of the letters that represent the five cards. In each of the three research procedures that have been developed and used to date, subjects are asked to consider one particular decision in expressing their preferences, such as their initial surgical treatment for breast cancer. Data obtained through administration of the CPS is meaningful only insofar as one particular decision of reference has been clearly identified.

1. Comparing every possible subset of two cards by hand: The first procedure is designed for use in cases in which the investigator has good control over the testing procedure and is committed to minimizing error. Such a case would be one in which the investigator has a single research assistant for whom extensive training can be offered, and in which a direct test of the hypothesis is essential. In addition, this procedure is restricted to clinical situations in which subject fatigue is not an issue.

This sorting procedure involves successive comparisons of all possible combinations of subsets of two of the five cards. The subject makes 10 paired comparisons \([n(n-1)/2]\). These pairs can be identified beforehand and arranged to obtain the maximal distance between the maximal number of items (Ross, 1974). The pairs are AB, BC, CD, DE, AC, BD, CE, AD, BE, and AE.

This method ensures that the subjects determine their rank ordering of preferences only after they have considered every possible combination of two cards. This approach minimizes measurement error, as evidenced by the results of a survey of 436 cancer patients: 63% fell directly on the hypothesized psychological dimension when this method was used.

2. Random-order presentation of the cards by hand: The second procedure is useful in instances where multiple data collectors with varying levels of education and ability might be employed, and in instances where a direct test of the hypothesis is less important. For example, the dimensionality of the construct in the population being tested might have been established in previous research.

The five cards are placed in random order through shuffling. The first two cards are placed in front of the subject, who is asked to
select the preferred card. The preferred card is placed on top of the non-preferred card. Then the next card is removed from the deck and placed beside the new stack of two cards. The subject is asked to compare the new card to the most preferred card. If the subject still prefers the previous card over the new one, the previous card is flipped over and the new card is compared to the next one in the new stack. If the subject prefers the new card, the new card is placed between the two cards in the new stack; if the previous second card is preferred, the new one is placed last in the new stack. This process continues until the subject’s entire preference order is unfolded. The subject will make between five and 10 paired comparisons, depending on which card is drawn first, the order of the pack of cards, and the subject’s ideal point. While easier to administer in the field, this approach leads to greater measurement error. For example, in a survey of the public, 53% of subjects fell directly on the hypothesized dimension (compared to the 63% of patients described above) (Degner & Sloan, 1992).

3. Fixed-order presentation of the cards by hand: The five cards are placed in the following fixed order: BDCEA. The procedure described in the above random-order presentation is used, beginning with the first two cards — B and D. Once the preferred card is selected, the next card (C) is compared to the preferred card, and so on, as described above. This procedure has proved to be very useful in clinical populations, since subjects can locate their ideal point in general terms (active, collaborative, passive) in their paired comparisons. A video has been developed to train research staff in this procedure.

Data Management

The back of each card is marked with a letter ranging from A to E. Immediately after the subject has completed the card sort, the preference order is recorded. For computer analysis, the data can be easily entered and manipulated as string variables. Subsequent variables are created as a result of whether the individual’s preference order falls on the hypothetical metric, and ordinal variables are created to represent their particular location on the metric.

Data Analysis

Analysis of unfolding data comprises two phases: (1) confirming the metric’s dimensionality, and (2) using scale scores to examine distribu-
tions and the impact of potential covariates. One of the datasets described in Degner and Sloan (1992) will be used to describe methods of data analysis. The exemplar dataset was collected from a consecutive sample of 436 newly diagnosed cancer patients who were tested in ambulatory oncology clinics. A total of 427 patients provided complete preference orders using the card-sort procedure described above. These preference orders provide the basis for the subsequent discussion and illustrations.

It is important for the investigator to verify that subjects actually use thought processes akin to the hypothesized dimension, to justify use of scale values. For any given five-point hypothetical scale, there are a possible 120 ordered permutations. The unfolding model holds that for any given hypothesized scale only a small subset of the 120 ordered responses (I, or individual, scales) will be transitive (see Figure 4). In this context, “transitivity” means that the subject’s response indicates they understood that the hypothesized construct lies along a continuum from A to E. This comes from the ideal point model, which takes into account the relative positions of the stimuli as well as their midpoints. For example, the person who provides the preference order BACDE has crossed the AB midpoint, so their ideal point is closer to B than to A. A person whose ideal point is located just to the left of the C item on the scale should give the preference order CDBAE, representing the individual’s relative distance from the five points on the continuum. A response of CBEAD would indicate that the person is saying they think item E is closest to items B and C on the metric, which it is not. According to Coombs, in this instance the individual’s score has “fallen off the metric,” because their ordered response makes no sense given the underlying theory. Such a preference order is referred to as “intransitive.” For any given five-point metric, there are only 11 transitive ordered (ordinal level) responses. If the true underlying metric is ABCDE, then the transitive responses are ABCDE, BACDE, BCADE, BCDAE, CBDAE, CDBAE, CDBEA, CDEBA, DCEBA, DECBA, and EDCBA. All other permutations are declared intransitive. Each metric has its polar permutations, which are exact reversals of one another. For example, the ABCDE metric has poles of ABCDE and its reverse, EDCBA.

Coombs maintains that if “50% plus one” of the experimental subjects’ preference orders fall on the metric, the scale is reliable. He also maintains that for the responses to form a scale a reversal must be present. This simple approach to evaluating the metric can be attributed to the fact that advanced statistical packages did not exist when Coombs formulated his theory. Today, all possible metrics can be exam-
ined to determine whether the hypothesized one is the only sensible one. For any given five-point metric, only 60 possible competing models can fit the data.

Using the SAS (SAS Institute, 1985) programming language, programs were developed to evaluate every one of the 60 metrics and produce summary statistics. Partial output of the program is summarized in Table 1 for the 427 cancer patients. It must be noted that presence or absence of a reversal is now no longer a prohibiting qualification to acceptance of a metric. The program merely runs through each model and notes various statistics that can be used for verification purposes. It then ranks the models by the number of valid responses in the dataset, notes whether a reversal is present, and notes the number of empty cells in each model.

As illustrated in Table 1, the hypothesized ABCDE scale is the only model in which more than 50% of the respondents’ answers correspond to one of its 11 transitive preference orders, or “cells.” No cells are empty, which means that each of the 11 valid responses appeared at least once in the dataset. There was a reversal for the ABCDE metric in the dataset, which means that at least one observation was made at each of the two poles (ABCDE and EDCBA). This would suggest that cancer patients understand the hypothesized construct.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Name</th>
<th>Valid</th>
<th>Valid %</th>
<th>Invalid</th>
<th>Invalid %</th>
<th>Empty Cell</th>
<th>Reversal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>ABCDE</td>
<td>282</td>
<td>66.0422</td>
<td>145</td>
<td>33.958</td>
<td>0</td>
<td>Y</td>
</tr>
<tr>
<td>6</td>
<td>ABEDC</td>
<td>184</td>
<td>43.0913</td>
<td>243</td>
<td>56.909</td>
<td>6</td>
<td>N</td>
</tr>
<tr>
<td>3</td>
<td>ABDCE</td>
<td>154</td>
<td>36.0656</td>
<td>273</td>
<td>63.934</td>
<td>2</td>
<td>N</td>
</tr>
<tr>
<td>4</td>
<td>ABDEC</td>
<td>128</td>
<td>29.9766</td>
<td>299</td>
<td>70.023</td>
<td>5</td>
<td>N</td>
</tr>
<tr>
<td>24</td>
<td>AEDCB</td>
<td>128</td>
<td>29.9766</td>
<td>299</td>
<td>70.023</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>2</td>
<td>ABCED</td>
<td>125</td>
<td>29.2740</td>
<td>302</td>
<td>70.726</td>
<td>7</td>
<td>N</td>
</tr>
<tr>
<td>60</td>
<td>DCBAE</td>
<td>104</td>
<td>24.3560</td>
<td>323</td>
<td>75.644</td>
<td>5</td>
<td>N</td>
</tr>
<tr>
<td>5</td>
<td>ABECED</td>
<td>96</td>
<td>22.4824</td>
<td>331</td>
<td>77.518</td>
<td>7</td>
<td>N</td>
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<tr>
<td>22</td>
<td>AECDB</td>
<td>85</td>
<td>19.9063</td>
<td>342</td>
<td>80.094</td>
<td>5</td>
<td>N</td>
</tr>
<tr>
<td>12</td>
<td>ACEDB</td>
<td>83</td>
<td>19.4379</td>
<td>344</td>
<td>80.562</td>
<td>5</td>
<td>N</td>
</tr>
</tbody>
</table>
The only other metric that could possibly compete with the posited ABCDE scale is the ABEDC dimension. Although it fails to meet the criterion of 50% plus one, this possibility should be fully explored. Table 2 shows the respondents’ detailed frequency distributions along the two competing metrics. The ABCDE metric has a reasonable distribution along its entirety, whereas the ABEDC metric is half empty. Coombs would reject this metric outright on the basis of his second criterion, because no reversal is present.

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABCDE</td>
<td>5</td>
<td>1.1710</td>
</tr>
<tr>
<td>BACDE</td>
<td>12</td>
<td>2.8103</td>
</tr>
<tr>
<td>BCDAE</td>
<td>10</td>
<td>2.3419</td>
</tr>
<tr>
<td>BCDAE</td>
<td>7</td>
<td>1.6393</td>
</tr>
<tr>
<td>CBDAE</td>
<td>18</td>
<td>4.2155</td>
</tr>
<tr>
<td>CDBAE</td>
<td>20</td>
<td>4.6838</td>
</tr>
<tr>
<td>CDBEA</td>
<td>27</td>
<td>6.3232</td>
</tr>
<tr>
<td>CDEBA</td>
<td>16</td>
<td>3.7471</td>
</tr>
<tr>
<td>DCEBA</td>
<td>61</td>
<td>14.2857</td>
</tr>
<tr>
<td>DECBA</td>
<td>34</td>
<td>7.9625</td>
</tr>
<tr>
<td>EDCBA</td>
<td>72</td>
<td>16.8618</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Answer</th>
<th>Count</th>
<th>Percent</th>
</tr>
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<tbody>
<tr>
<td>ABEDC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>BAEDC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>BEADC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>BEDAC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>EBDAC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>EDBAC</td>
<td>0</td>
<td>0.0000</td>
</tr>
<tr>
<td>EDBCA</td>
<td>1</td>
<td>0.2342</td>
</tr>
<tr>
<td>EDCBA</td>
<td>72</td>
<td>16.8616</td>
</tr>
<tr>
<td>DECBA</td>
<td>34</td>
<td>7.9625</td>
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<tr>
<td>DCEBA</td>
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<td>14.2857</td>
</tr>
<tr>
<td>CDEBA</td>
<td>16</td>
<td>3.7471</td>
</tr>
</tbody>
</table>
Once the ABCDE metric has been assessed as being sound, ordinal scale values from 1 to 11 can be assigned to subjects whose preference orders fell directly on the metric, and distributions and effects of covariates can be examined. Modelling is most easily and appropriately done via McCullagh's (1980) regression models for ordinal data. However, a major question remains: What to do with the people who responded "incorrectly"? Coombs (1976) suggests that such people, for the remainder of the analysis, should be dropped from consideration. However, the idea of discarding a substantial portion of a dataset is not appealing. Several methods are possible at this point. Figure 5 shows the distribution of respondents on and off the ABCDE metric. If one assumes that the people who fell off the metric made a mistake, such mistakes might naturally occur at random. This is clearly not the case for this distribution. Most of the mistakes occur in the area between items C and D on the scale, which suggests that these two stimuli were not a "just noticeable difference" apart in this sample and as a result subjects were likely to confuse them. One alternative would be to collapse items C and D and then redistribute the scores. Another would be to rank the preference orders from 1 to 120 (or the number observed out of the total possible number of ordered permutations) and proceed as if an ordinal variable had been observed. Either route would allow the investigator to retain all of the observations. More detail about this approach and analytic procedure is described in Sloan (1994).

A naturally occurring categorical variable is the person's most preferred role in treatment decision-making. For analysis purposes, five categories can be used (A, B, C, D, E), or preference orders can be reclassified into Active (A, B), Collaborative (C), and Passive (D, E). Another approach is to create a categorical variable based on the person's two most preferred roles: Active-Active (AB, BA), Active-Collaborative (BC), Collaborative-Active (CB), Collaborative-Passive (CD), Passive-Collaborative (DC), and Passive-Passive (DE, ED) (Hack, Degner, & Dyck, 1994). Ordinal categorical analysis associated with chi-square and other cross-tabulational measures can be applied to these data.
Figure 5  Distribution of Respondents On and Off ABCDE Metric

Unfolded Role Preference On ABCDE Metric

☐ Yes  ■ No

Frequency count

34
Clinical Applications

The CPS is also useful as a clinical-assessment tool. Two approaches have been developed for its application.

1. The "pick one" approach: Patients were interviewed privately prior to their first visit to the oncologist, as part of a nursing intervention (Neufeld, Degner, & Dick, 1993). They were asked to consider the five cards and select the one that fell closest to their preferred role in the treatment decisions to be discussed with their oncologist that day. Patients were able to read through the cards, which were laid out in an order ranging from most to least control, and select the one that best represented their preferred role in decision-making. Then they were asked to discuss the extent to which the statement on the card actually represented their preference. This is important in the clinical context, because an individual's ideal point might fall between two items. Many patients were surprised that they were offered this choice, thinking that they were just going to have to accept their physician's recommendation about treatment. Seeing the range of alternatives allowed them to think differently about participation in decision-making. The CPS has proven to be useful for eliciting input from patients and helping clinicians gain insight into patient preferences. More information about applying the CPS in this manner is available in the form of an audiotape and manual (Triclinica Communications, 1993).

2. Fixed-order presentation of the cards by computer: The fixed-order presentation approach has been adapted for use on a touch-screen computer. After an introductory screen describes the task, two cards appear side by side on the screen in the fixed order described under Research Applications above. When the subject touches the screen at their preferred card, the next two cards automatically appear. At the end of the task, a printed diagram shows the patient's preferred level of involvement in decision-making on the keep/share/give-away control dimension (see Figure 2), with an arrow indicating their ideal point. This program is currently being evaluated in a clinical trial to determine whether women with breast cancer who are coached using this program and given the printout prior to their medical visit achieve a greater degree of involvement in treatment decision-making than women who are not coached using the computer program.
Preferred versus Actual Role in Decision-Making

Sutherland et al. (1989) used the original statements of Strull et al. (1984) in studying 60 radiotherapy patients at the Princess Margaret Hospital in Toronto. Patients were asked to select their preferred role in decision-making using the “pick one” approach described above, but they were also asked to indicate which role they had actually assumed in making treatment decisions. This approach was used in a recent study of women with breast cancer (Degner et al., 1997). Once the patient had completed the card sort and the result had been recorded, the five cards were laid out on a surface in the order the patient had picked. They were then asked to reconsider the order, and indicate the card that best represented the role they had played with respect to their original surgical treatment. Patients were able to easily distinguish between their preferred role and actual role in treatment decision-making.

Data Management and Analysis

Comparison of respondents’ most preferred role and the role they believe they actually assumed in decision-making provides an important index of how consumers believe various settings are accommodating their preferences. While chi-square analysis gives an indication of whether there is significant incongruence between preferred role and actual role, displaying respondents’ preferred and actual roles allows for more precise examination of the placement, direction, and extent of the incongruence. It could lie in the direction of being asked to make choices they prefer not to make, as well as in the direction of not achieving a satisfactory degree of involvement. The greater the distance between the individual’s actual role and preferred role, the greater the incongruence.

This analysis approach is best illustrated in a recent survey of 1,012 women with breast cancer (Degner et al., 1997). Only 42% of all the women believed they had achieved their preferred role in decision-making for their initial surgical treatment. Analysis of incongruences between preferred role and actual role revealed that only 21% of the women who wanted the most active roles in decision-making achieved them. However, a small group of women (14.9%) believed they had been pushed to assume more decisional control than they wanted. This type of analysis is very useful in describing patients’ perspectives on their experiences around decisional control in our health-care system. The potential to reduce discrepancies between preferred role and actual role in decision-making also provides an opportunity for evaluation of specific nursing interventions by measuring a specific outcome (Davison & Degner, 1997).
Samples Studied

To date, the CPS has been used with a variety of samples. The sample of 436 newly diagnosed cancer patients was compared to a sample of 482 members of the public who were asked to choose the role they would like to play in treatment decision-making if they were diagnosed with cancer (Degner & Sloan, 1992). While the majority of cancer patients (59%) wanted physicians to make treatment decisions on their behalf, most members of the public (64%) thought they would want to make their own treatment decisions if they got cancer. Other projects have involved testing the scale in smaller samples of newly diagnosed prostate-cancer patients (Davison et al., 1995) and newly diagnosed breast-cancer patients (Bilodeau & Degner, 1996; Hack et al., 1994). A larger study of breast-cancer patients at a variety of points in their disease trajectory found that 22% preferred an active role, 44% a collaborative role, and 34% a passive role in decision-making (Degner et al., 1997). Another study was undertaken, in Britain, with 150 women with newly diagnosed breast cancer and 200 women with benign breast problems (Beaver et al., 1996). The CPS has also been adapted to study preferences for decisional control in kidney dialysis (Kaprowy, 1991), in vitro fertilization (Thompson, 1990), and childbirth (Gupton, 1994).

Because the items in the CPS use general wording, they are applicable to a wide variety of health-related conditions. Alternatively, the items can be revised, and graphics developed, to suit the context under study. Determining the proportion of preference orders obtained in the new context that fall directly on the hypothesized dimension provides direct evidence about whether the revised stimuli form a scale.

Evidence for Validity and Reliability

The construct validity of the CPS was established by defining the construct in the context of a grounded theory, and, to date, the scale has proven a useful tool in epidemiological surveys whose goal is to establish estimates of the prevalence of different preferences and to determine the best predictors of these preferences. However, the usefulness of the measure in longitudinal as opposed to cross-sectional prediction remains to be established. Currently, work is being conducted to determine whether women with breast cancer who desire more involvement in decision-making at the time of diagnosis, and/or achieve more involvement, experience less anxiety, depression, and post-decisional regret three years post-diagnosis, as suggested by Fallowfield’s long-term follow-up of breast-cancer patients in England (Fallowfield, Hall, Maquire, Baum, & A’Hern, 1994). This study also addresses the issue of
whether preferences change over time. Davison and Degner (1997) have already demonstrated that a nursing intervention to empower men with prostate cancer did allow the patients to assume more active roles in decision-making, as measured by the CPS, and also resulted in lower anxiety levels.

In each of the major studies undertaken with the control preferences scale in cancer populations, unfolding analysis has demonstrated that the scale has met Coombs's criterion of 50% plus 1 subjects falling on the hypothesized dimension (see Table 3). Similar results were obtained for members of the general public (56%). Given the fact that out of 60 possible scales that could emerge from n=5 stimuli, only one has met the scaling criterion in study after study, the CPS has demonstrated reliability in cancer populations. However, similar testing would have to be undertaken should the scale be used to estimate preferences in different populations or regarding health-care decisions other than those concerning medical treatment. As Table 3 demonstrates, method of presentation does influence the degree of measurement error, with random order being less satisfactory than the other two methods in a research context. Indeed in Beaver et al.'s (1996) study of 200 women with benign breast disease, which used random-order presentation, only 49% of subjects fell on the ABCDE dimension; the study thereby failed to meet this reliability criterion.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Reliability of the CPS with Cancer Patients</th>
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<tr>
<td>Criterion</td>
<td>Study</td>
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<tr>
<td>50% plus one subjects fall on hypothesized dimension ABCDE</td>
<td>Degner &amp; Sloan (1992)</td>
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<td></td>
<td>Beaver et al. (1996)</td>
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<td>Degner et al. (1997)</td>
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Discussion

Early attempts to understand consumer preferences took a dichotomous approach, asking subjects to select one of two statements as their preferred role in health-care decision-making: either “I prefer to participate in decisions about my medical care and treatment” or “I prefer to leave decisions about my medical care and treatment up to my doctor” (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Subsequently, Likert scaling was used with investigator-selected items to measure the
The Control Preferences Scale

general desire for control in health care (Greenfield et al., 1985; Krantz et al., 1980; Smith, Wallston, Wallston, Forsberg, & King, 1984). A variant of this approach was taken by Ende, Kazi, Ash, and Moskowitz (1989), who used a five-point rating scale with six general items and three items related to each of three hypothetical health problems, for a total of 15 items. Other investigators have used a “pick one” approach with three or five statements similar to ones on the physician-patient dimension of the CPS (Larsson, Svardsoo, Wedel, & Saljo, 1989; Strull et al., 1984; Sutherland et al., 1989), or a Q-sort in which one factor was described as “decisional control” (Dennis, 1987).

The CPS offers several advantages over previously published measures. First, the data can be presented in a manner that is easily understood by clinicians. Distributions of subjects along the control preferences dimension provide more meaningful information to guide clinical practice than do mean values. Second, the CPS scale values can be used with regression models for ordinal data. As a result, the scale offers the same advantage as Likert scaling in determining the effect of covariates, and is an improvement over the “pick one” approach, in which the effect of covariates can be examined only on a univariate basis. Third, examination of all preference orders allows for the emergence of competing metrics that could offer other explanations of consumer preferences in subsets of the populations under study. Fourth, the CPS can identify the degree of congruence or incongruence between preferred role and actual role. Finally, the CPS has been demonstrated to be useful as a clinical screening tool as well as a research measure.

The use of a “pick one of two statements” approach may lead to inaccurate conclusions both about distributions of preferences and about the effects of covariates on consumer preferences. Previous studies (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Casselith et al., 1980) may have seriously overestimated the proportion of people who want to participate in treatment decision-making, simply because of the limited number of stimuli presented to subjects. Investigators using the “pick one of two statements” approach have concluded that age and education are related to consumer preferences, with younger, more highly educated people wanting more control in treatment decision-making. While this univariate effect is also reported by investigators using scaled data, both the Ende et al. (1989) study using a Likert scale and our study using the CPS (Degner & Sloan, 1992) found that less than 15% of the variance in preferences was accounted for by any predictive model. The use of characteristics such as age and education level to judge an individual’s role preferences clearly could be misleading and potentially cause stereotyping of subgroups.
Individual assessment of consumer preferences using a screening measure such as the CPS remains the best clinical approach, and one that is currently being evaluated in the context of a clinical trial.

Previous intervention studies to enhance consumer control in health care have largely proceeded from the assumption that all subjects want to exercise decisional control. As a result, few attempts have been made to examine the possible interaction effect between control preferences and the opportunity to participate in making choices on health-care outcomes (Wallston et al., 1991). Congruence between preferred role and actual role may be more important than the actual assumed role (Haug & Lavin, 1981). The CPS provides a quick and practical approach to blocking subjects in order to examine the interaction effect of control preferences and control-enhancing interventions on outcomes.

The CPS offers a new approach to eliciting consumer preferences about participating in health-care decision-making. The scale has been used by hundreds of people, ranging from members of the general public to members of highly stressed populations, and has proven to be easily and quickly administered. Even people with relatively low levels of education can successfully complete the paired comparisons. Scaling procedures have demonstrated that people in a variety of populations do have systematic preferences about keeping, sharing, or relinquishing control over health-care decisions. The CPS should prove to be a useful measure for both clinicians and researchers as they attempt to foster consumer involvement in a manner that leads to improved health-care outcomes and better utilization of scarce resources.

References


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