# Validation of Client Decision-Making Instruments in the Context of Psychiatry

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Nous avons évalué les propriétés psychométriques des instruments qui mesurent le conflit décisionnel, l'efficacité personnelle dans la prise de décision et la maîtrise émotionnelle de la décision chez 94 schizophrènes qui envisageaient de poursuivre leur traitement avec des injections de neuroleptiques à action prolongée. Les échelles de décision montraient une bonne cohérence interne (entre 0,78 et 0,84) et se distinguaient de façon significative (p < 0,000 à 0,037) entre les malades qui exprimaient leur certitude et ceux qui exprimaient leur incertitude à propos de leur décision de continuer ou non un traitement. Les échelles peuvent être utiles pour ce qui concerne les gens souffrant de troubles psychiatriques; elles permettent d'établir les facteurs qui participent à la difficulté de prendre une décision concernant le traitement et d'évaluer les interventions possibles pour aider à la prise de décision.

We evaluated the psychometric properties of instruments measuring decisional conflict, decision self-efficacy, and decision emotional control with 94 clients diagnosed with schizophrenia who were considering the continuation of treatment with long-acting antipsychotic injections. The decision scales had adequate internal consistency (range 0.78 to 0.84) and discriminated significantly (p<0.000 to 0.037) between clients who expressed certainty and those who expressed uncertainty regarding decisions to continue with treatment. The scales may be useful in psychiatric populations, in identifying the factors contributing to difficulty in decision-making regarding treatment and evaluating decision-supporting interventions.

In psychiatric/mental health care, as in other health-care contexts, recent trends have been toward increased consumer involvement and empowerment (Graham, 1988; National Health and Welfare, 1991). These changes encompass a reversal of the power relationship between clients and clinicians, with an increase in clients' exercise of control over their own health and treatment decisions (Church, 1989). The *Mental Health Act* (Ministry of Health, 1992) and the proposed *Consent to Treatment Act* (College of Nurses, 1993) are consistent with this new emphasis on informed choice (Evans, 1987), rather than merely informed consent, on the part of the client.

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Research evaluating client decision-making is in its infancy. A review of the psychiatric literature indicated only one study examining psychiatric disturbance and decision-making. Bradford, Mann, and Kalucy (1986) used Janis and Mann's (1977) conflict theory and Edwards' (1961) expectancy-value theory to measure decision-making in a variety of clients with psychiatric disturbance; 59% of the participants were diagnosed with mood disorder; none was diagnosed with schizophrenia. The study focused on decision-making generally rather than on making a specific treatment decision. The authors concluded that measures based on both models yielded results consistent with assumptions that the greater the disturbance the greater the level of decisional conflict, the lower the level of confidence the higher the level of irrational choice and the more pessimistic and distorted the information processing. There are no published studies examining treatment decision-making by clients diagnosed with schizophrenia.

One method of promoting client choice is the use of decision aids; these describe treatment alternatives using probabilities tailored to the client's clinical profile and outlining the consequences of the choices made. In addition, some aids are used to clarify values and assist in applying the decision taken. Decision aids are currently being used to help clients make choices about cancer treatments (Levine, Gafni, Markham, & MacFarlane, 1992), hormone replacement therapy (O'Connor, Tugwell, & Wells, 1995; Rothert, Holmes, & Rovner, 1993), surgery (Kasper, Mulley, & Wennberg, 1992), and clinical trial entry (Llewellyn-Thomas, McGreal, Thiel, Fine, & Erlichman, 1991). Nurses in Canada (Neufeld, Degner, & Dick, 1993), Britain (Greene, 1992), and the U.S. (Phillips, Rempusheski, Puopolo, Naccarato, & Mamallateratt, 1990) are being encouraged to identify clients' information needs and to provide relevant information to facilitate their active and informed participation in their own treatment.

Decision aids have not been developed for use in psychiatry. Davidhizar (1982) and Lyons and Fulkerson (1984) have demonstrated that psychiatric clients diagnosed with schizophrenia exhibit difficulties in perception, cognition, and affect. Therefore, it is critical to appropriately modify decision aids and evaluate their adequacy for clients diagnosed with schizophrenia. Do decisional aids contribute to more effective choices, or do they result in an additional burden for clients who are already experiencing difficulty with cognition and affect? Answering this question requires evaluation measures capable of detecting the cognitive, social, and emotional aspects of making an informed choice.

The objective of the present study was to validate instruments developed to measure the cognitive, social, and emotional aspects of decisions made by clients with schizophrenia. Three scales developed by O'Connor for use in non-psychiatric populations were adapted for clients with schizophrenia and evaluated for reliability and validity: the Decisional Conflict Scale (DCS), measuring the cognitive aspects of decision-making (O'Connor, 1995a); the Decision Self-Efficacy Scale (DSES), measuring the social aspects of decision-making; and the Decision Emotional Control Scale (DECS), measuring the affective dimension of decision-making. The information provided by this study would be useful in identifying the difficulties in decision-making experienced by clients with schizophrenia and the factors that contribute to such difficulties. In addition, these data could be used to fine-tune the development of decision aids for clients with schizophrenia as well as for other psychiatric clients.

## Conceptual Framework

The original decision scales were developed (O'Connor, 1995a) using a conceptual framework derived from the construct of decisional conflict (Janis & Mann, 1977; North American Nurses Diagnosis Association, 1992; O'Connor, 1993). Decisional conflict, a state of uncertainty about the course of action to take, tends to occur when choices are being made that involve risk, significant gains and losses, the need to make value trade-offs, and anticipated regret over the positive aspects of rejected options (Janis & Mann; North American Nurses Diagnosis Association; O'Connor, 1993; O'Connor & D'Amico, 1990; Sjoberg, 1983). Decisional conflict is characterized by verbalization of uncertainty, vacillation between choices, delayed decision-making, and questioning of personal values and beliefs while attempting to reach a decision. Self-focusing and signs of stress may also be seen (O'Connor, 1995a).

Although decisional conflict often arises from the dilemma inherent in the decision, several modifiable factors are hypothesized to contribute to it, including: lack of information about available alternatives and the accompanying risks and benefits, unclear values, lack of skills or resources needed to make or implement a decision, emotional distress, and unwanted pressure from important others (O'Connor, 1993; O'Connor & D'Amico, 1990). The following empirical evidence supports these hypothesized relationships for health decisions. Surgical patients who felt uninformed about the nature, consequences, and extent of surgical procedures had greater difficulty reaching decisions

(Larsson, Svardsudd, Wedel, & Salio, 1989). Medical patients who experienced high levels of emotional distress had difficulty thinking clearly, which led to interference with decision-making (Fitten & Waite, 1990; Scott, 1983). It has been demonstrated that uncertainty when making a choice is greater among those who feel uninformed about options, are unclear about personal values, and sense pressure from others (O'Connor, 1995a). Moreover, decision-supporting interventions have been shown to reduce uncertainty and improve comprehension and awareness of personal values (O'Connor et al., 1995).

Theoretically, decision aids have the potential to reduce decisional conflict, by tackling the hypothesized causes of the conflict and by increasing self-efficacy and emotional control (O'Connor, 1993, 1995a; O'Connor & D'Amico, 1990). For example, lack of information can be remedied by providing accurate information about alternatives and describing associated risks and benefits. Value-clarification exercises can help clients who are unclear about the relative importance of the attributes in a decision and the implicit trade-offs they will be making in selecting an alternative. Skill deficits in implementing decisions and handling unwanted pressure can be addressed via learning exercises such as rehearsing and role-playing. Decision aids may also reduce emotional distress by increasing clients' personal control over difficult situations. Adequate information and participation in decision-making enhance cognitive and environmental control, which are crucial in reducing stress-related signs and symptoms (Johnson, Fuller, & Endress, 1978; Padilla et al., 1981; Watkins, Weaver, & Odegaard, 1986). Thus decision aids may lead to effective decision-making - whereby clients make and act on choices that are informed and consistent with their personal values.

#### Methods

# Original Decisional Measures

The Decisional Conflict Scale (DCS) includes three subscales, eliciting (1) the client's uncertainty in making a health decision, (2) factors contributing to this uncertainty, and (3) the client's perceived effective decision-making. The items were developed from the construct of decisional conflict and validated by a panel of decision-making experts. The total number of items is 16, three measuring uncertainty, nine measuring contributing factors, and four measuring perception of effective decision-making. Each item is paired with a five-point Likert response

scale anchored by "strongly agree" and "strongly disagree" (O'Connor, 1995a). The DCS has been evaluated with more than 1,000 individuals making preventative decisions about immunization and breast screening (O'Connor, 1995a). The test-retest reliability coefficient is 0.81. Internal consistency coefficients for the scale range from 0.78 to 0.92. The DCS discriminates significantly (p<0.001) between those with (a) strong intentions to either accept or decline invitations to receive health interventions and (b) uncertain intentions. The scale also discriminates significantly (p<0.0002) between (a) those who accept or reject health interventions and (b) those who delay their decision. There is weak inverse correlation (r= -0.16, p<0.05) between the DCS and knowledge test scores.

The Decision Self-Efficacy Scale (DSES) was based on Bandura's (1977) concept of self-efficacy. Bandura describes self-efficacy as a feeling of adequacy and efficiency in dealing with life situations. More specifically, O'Connor views self-efficacy as perceived ability to engage in treatment-related behaviours. The DSES is an 11-item instrument with a five-point response scale ranging from 0 (not at all confident) to 4 (very confident). The measure elicits clients' appraisal of their abilities to engage in the task of obtaining information about treatment options, expressing their concerns and views, and making an informed choice. The focus is on their social role in working with their health team to carry out this task. Face validity was established by a panel of experts in decision-making. Internal consistency was established with 60 women considering hormone replacement therapy, and the alpha coefficient was 0.89 (O'Connor, 1995b).

The Decision Emotional Control Scale (DECS) has six items describing various emotions (strong, secure, in control, afraid, confused, and frustrated) related to making an informed choice. Respondents indicate the degree to which they are experiencing each feeling on a five-point response scale ranging from 0 (not at all) to 4 (very much). This measure was validated by an expert panel and is currently being evaluated with women considering hormone replacement therapy (O'Connor, 1995b).

# Modification of the Decisional Measures

The original scales were modified for use with clients diagnosed with schizophrenia following consultation with a panel of psychiatric clinicians, including psychiatrists, nurses, and social workers from the schizophrenia clinic. Individual items were also modified to conform to

the choice being made in this study – namely, whether to continue with long-acting antipsychotic injections. Clinicians expressed concern that many of their clients diagnosed with schizophrenia demonstrate concreteness in thinking and would have difficulty with the abstract thinking needed to deal with the five-point scales. For example, they would be unable to distinguish between responses of "agree" and "strongly agree" as well as between "disagree" and "strongly disagree." They would likely be able to indicate "yes," "no," or "unsure" for each item, but not the *degree* of positive or negative agreement. The response scales were simplified to reflect this reality.

The DCS was simplified by reducing the Likert scale from a fivepoint to a three-point scale. Responses were scored as 1 (yes or agree), 2 (unsure), and 3 (no or disagree), with negative statements having reverse scoring. Therefore, higher scores indicated greater decisional conflict.

Further modifications were made following completion of a small pilot study of the instruments with four randomly selected clients from the clinic who had been diagnosed with schizophrenia. Two of these exhibited concrete thinking. All four experienced difficulty with an item asking them to determine which was most important, controlling the symptoms of schizophrenia or avoiding side effects. For example, the original item was presented as "I'm not sure what's worse: having the inconvenience and side effects of the injections or getting back my symptoms of schizophrenia." The item was revised to elicit a clearer response from clients, as follows: "Which is more important? Controlling symptoms of schizophrenia; avoiding side effects of medication; both are equal; unsure." A second item that caused confusion was originally stated as "I feel that this decision is mine alone." The item was changed to "I have the right amount of support from others in making this choice." Likewise, the item "I expect to carry out the decision I made" was changed to "I expect to stick with my decision." The remainder of the items posed no difficulty for the four pilot clients. All clients suggested that the research assistant be available to read and explain items to participants in the major study.

The DSES was similarly simplified by reducing the five-item summative response scale to three items, consisting of 1 (a lot confident), 2 (a little confident), and 3 (not confident). All items were positively phrased; therefore, higher scoring indicated greater problems with decision self-efficacy. Clients in the pilot study completed the items without difficulty.

The DECS was also reduced from a five-item summative response scale to three items, consisting of 1 (a lot), 2 (a little), and 3 (not at all). Negative feelings had reverse scoring; therefore, higher scoring indicated greater problems with emotions. One item, "strong," was deleted because two clients in the pilot study interpreted it as a physical descriptor rather than an emotional one.

As suggested in the literature (Davidhizar, 1982) and confirmed by clients in the pilot study, the instruments were presented to clients both verbally and visually, to increase the likelihood of comprehension.

## Establishing Reliability and Validity of Modified Decision Scales

Psychosocial scales, such as the decision scales used in this study, are frequently evaluated for reliability by examining their internal consistency (Polit & Hungler, 1991). Nunnally (1978) recommends evaluating internal consistency reliability on all new instruments, since item sampling is the major source of error. Cronbach's alpha was used to assess the reliability of the decision scales in this study, since it renders an estimate of the split-half correlations for all possibilities of dividing the measure into two halves (Polit & Hungler).

To ensure that the decision instruments corresponded to the theories of decisional conflict and self-efficacy, construct validity was tested. A common method of construct validation is the known-groups approach (Kerlinger, 1973, p. 467), in which the instruments are administered to groups who are expected to differ on the attributes being measured. Consistent with the theory and research conducted in other contexts (O'Connor, 1995a), we hypothesized that individuals who were unsure or who delayed making their decisions would have higher decisional conflict, decision self-efficacy, and decision emotional control scores than individuals who decided to continue. In this study, following administration of information about the risks and benefits of longacting injections, participants made a decision. They were then assigned to one of three groups, according to their decision – to continue taking injections, discontinue injections, or delay reaching a decision.

### Sample

The modified scales were tested with a convenience sample of 94 clients diagnosed with schizophrenia according to the DSM IIIR. All clients attended the schizophrenia clinic at a major psychiatric hospital in Ottawa over a 10-week period from April to June 1993. Clients who

were deemed by the attending psychiatrists to be acutely psychotic, or those who were diagnosed primarily as schizo-affective, were excluded. Nurses working in the clinic approached eligible clients and asked for their cooperation in meeting with the research assistant, who explained the purpose of the study. Written informed consent was obtained from those clients who agreed to participate. They were told that the purpose of the study was to "help people with schizophrenia make better decisions about taking medicine" and that we needed their help to make sure the information we were providing made sense. Clients were assured of confidentiality and were assured that their decision whether or not to participate would not affect the care they normally received in the clinic.

#### Procedure

Information about the risks and benefits of taking long-acting antipsychotic injections was presented to clients in a one-to-one setting in the clinic by the research assistant. Clients were then asked to make a decision about continuing with their injections, with either a yes, no, or unsure/delay response. The DCS, DSES, and DECS were then administered and clients were asked to reflect on their choices.

The information about risks and benefits was based on the following evidence: The most common risks associated with antipsychotic injections and the most frequently cited reasons for non-compliance are the extrapyramidal side effects of akathisia, akinesia, rigidity of muscles, tremor, dystonia, and tardive dyskinesia (Anderson et al., 1990; Den Boer et al., 1990; Laux et al., 1990; Lewander, Westerbergh, & Morrison, 1990; Lindstrom et al., 1990; Mendlewicz et al., 1990; Patris et al., 1990). Based on these studies, the side effects of akathisia, akinesia, rigidity of muscles, and tremor were grouped together and the percentage of clients deemed likely to experience them was conservatively set at 40%; dystonia and tardive dyskinesia were also grouped and the percentage of clients likely to experience them was set at 20%. Several studies have identified the benefits of long-acting injections in controlling symptoms of schizophrenia and preventing rehospitalization (Crawford & Forrest, 1974; Dencker, Leep, & Malm, 1980; Hirsch, Gaind, Rohde, Stevens, & King, 1973; Hogarty, Goldberg, Schooler, & Ulrich, 1974; Hogarty et al., 1979; Rifkin, Quitkin, Rabiner, & Klein, 1977). Based on this research, the likelihood of controlling symptoms was determined to be 75%, of preventing rehospitalization 80%.

#### Results

## Sample

Sixty-eight (72%) of the respondents were male and 26 (28%) were female. Their ages ranged from 27 to 68 years, with a mean age of 41 years. All clients were able to speak and read English. All were presently taking long-acting antipsychotic injections; 86% had been taking them for more than five years, while only 2% had been taking injections for less than one year.

## Response Difficulty

The DCS, DSES, and DECS were administered, with some verbal explanation from the research assistant. Four (4%) respondents had some difficulty focusing on the task at hand, but with extra encouragement from the research assistant they were able to focus and continue with the study. All 94 clients completed all items on the DCS. Across all the items in the DSES and the DECS, missing responses ranged from 1% to 3%. One client was unable to complete the DSES and the DECS due to fatigue and inability to concentrate. The DSES and the DECS were the second and third instruments administered in the study. One client, who had been diagnosed with chronic paranoid schizophrenia, refused to complete the DSES because he believed he did not have a choice with respect to taking the long-acting antipsychotic injections.

# Reliability

Internal consistency for all scales was adequate, with an alpha coefficient of 0.78 for the DCS, 0.84 for the DSES, and 0.79 for the DECS.

# Validity

Eighty-two (87%) of the clients decided to continue treatment, nine (10%) were unsure about what to do or wanted to delay making their decision, and three (3%) decided to discontinue treatment. Because the proportion who decided to discontinue was so small, comparisons were made only between the delayers and the continuers.

As indicated in Table 1, the DCS, DSES, and DECS were consistent in discriminating between those clients who decided to continue treatment on the one hand and those who were unsure about or wanted to delay their decision on the other. As hypothesized, respondents who

were unsure or wanted to delay obtained higher scores on the DCS, indicating greater decisional conflict; higher scores on the DSES, indicating more difficulty with decision self-efficacy; and higher scores on the DECS, indicating greater difficulty with decision emotional control. Because the number of clients who decided to delay their decision was relatively small, we assessed the significant differences to determine whether they were a result of extreme scores for some participants (outliers); there were no outliers to explain the results.

Table 1 Mean Differences in DCS, DSES, and DECS scores between those who decided to continue treatment and those who were unsure or who delayed their decisions t test Scale **Decision Groups** p value Continue Delay/Unsure \*n = 82n = 9**Decisional Conflict** Possible range 16 = low conflict48 = high conflict Mean 20.9 29.8 < 0.000 (SD) (4.4)(3.3)Decision Self-Efficacy Possible range 11 = no problems 33 = considerable problems Mean 14.6 16.8 0.037 (SD) (4.3)(2.4)**Decision Emotional Control** Possible range 5 = no problems15 = considerable problems Mean 9.7 0.003 6.6 (SD) (2.3)(2.2)\* n varied slightly (79-82) for decision groups, due to missing responses.

#### Discussion

The DCS, DSES, and DECS met acceptable standards of validity and reliability despite the small numbers in each group. Nunnally (1978) suggests that alpha coefficients of 0.70 are acceptable for immature scales such as these.

The large number of clients who decided to continue with their injections and the accompanying small number who indicated uncertainty could be explained by the nature of the sample. Participants in the study were all being maintained on long-acting antipsychotic injections; they had experienced the risks and benefits and thus may not have perceived the decision as critically as those clients who would be making an initial decision to begin or refuse the injections. In addition, the participants were part of a supportive clinic environment and the majority would be expected to continue with treatment.

Although all three decision scales discriminated significantly among groups, scores were fairly low even in the uncertain group (see Table 1). These results may be attributable to the low-risk decisions studied. In order to evaluate further the usefulness of these decision scales, the study could be repeated with clients diagnosed with schizophrenia who are not linked with a specialized supportive clinic and those who are making initial decisions about beginning treatment. Using these clients and enlarging the sample size might result in larger numbers per group and thus also allow for validation of subscales.

The majority (97-99%) of clients in the study were able to respond to individual items on all three decision scales. This high response rate suggests that the scales are appropriate for use with clients diagnosed with schizophrenia. The majority of clients had no difficulty with the decision scales, perhaps because they were stabilized on medication. With the exception of two clients (2%), respondents accepted the active involvement of the research assistant, who read the items aloud. This involvement may also have contributed to the high completion rate for items on the decision scales.

In future studies, it would be useful to examine additional feeling concepts within the DECS. For example, one client (1%) suggested that anger be included, since many clients with schizophrenia are dealing with this emotion when they make decisions related to treatment.

In conclusion, the adapted DCS, DSES, and DECS met acceptable standards of reliability and validity in a psychiatric context. These decision scales may also be useful tools for assessing the *nature* of decisional

conflict in clients with schizophrenia, so that interventions can be tailored to the individual. For example, those clients who have a high degree of decisional conflict because of information deficits may require interventions that are distinctly different from those needed by clients who are unclear about their values or anticipate having implementation problems. Clinicians would thus have access to information to guide their decisions with respect to the time allotted to various interventions, such as information-giving, values clarification, or emotional support, depending on the deficits demonstrated by the client. In addition, these decision tools may be helpful in establishing optimum relationships with clients diagnosed with schizophrenia and thus contribute to actualizing a philosophy of increased consumer involvement, empowerment, and informed choice.

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