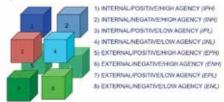
A Linguistic Approach to Improving Self-care and Compliance

In the adherence literature, over 200 variables have been examined to determine their association with patient adherence to self-care behaviours¹-³. Previous approaches have had either little predictive power or were dependent on epidemiologic variables that were not amenable to intervention. Ideally an adherence questionnaire should be simple to administer and provide a reliable classification that predicts individual adherence and generates actionable information. Herein we provide evidence that the CoMac Descriptor™, based upon linguistic analyses of patient statements regarding their disease, meets these criteria.

Main body Paragraphs:

Over the past several years, an interdisciplinary research group at Indiana University, consisting of linguists and healthcare professionals, has identified linguistic indicators in three domains related to adherence: control orientation, based on locus of control research4; agency, based on selfefficacy⁵; and affect or attitude and emotion⁶. Based upon this linguistic research⁷⁻¹⁰ and using the language that reveals a subject's worldviews on each of the domains, we have developed a questionnaire, the CoMac Descriptor™. The CoMac Descriptor™ relies on patient's self-identification with the actual words used by other patients with the same worldview. The instrument categorises patients into one of eight bins: internal or external control orientation, high or low agency, and positive or negative affect (Table 1). The questionnaire can be administered in 10 to 15 minutes. The data presented below describe the research that led to the development of the CoMac Descriptor™. Data are provided to show that the Descriptor™ can reliably predict self-care behaviour compliance in persons with type 2 diabetes and hypertension.

Table 1: Descripter™ Clusters



Recognising the importance of understanding the patient, the interdisciplinary research group at Indiana University conducted in-depth interviews of 43 English-speaking subjects with type 2 diabetes. They were analysed by domain by two to four coders into one of the eight bins (internal and external control, high and low agency and negative emotions). The linguistic feature systems (word use, sentence structure, and other expressions) for agency and control domains were generated using grounded theory analysis that has been extensively used in qualitative analyses of health communication. The linguistic features of affect expressions that were tested in this sample of diabetes patients came from a well-established linguistic theory of affect appraisal⁶.

The initial CoMac Descriptor™, based upon the results of these analyses, was a 35-item survey. Its validity was tested in 20 persons with diabetes as compared to the in-depth interviews of the same persons. The CoMac Descriptor™ responses and interviews were analysed independently from each other. The results from the CoMac Descriptor™ coding were compared to those of the interview coding to determine the concurrence of the domain placement of the interviews versus the CoMac Descriptor™. In this administration of the 35-item version, there was 75% agreement between CoMac Descriptor™ results and the linguistic analysis of individual interviews; the agreements between the CoMac Descriptor™ and control orientation, agency, and affect were 75%, 70%, and 80%, respectively. There was also 100% agreement on content validity arrived at through inter-rater reliability assessment by three content specialists in linguistics and test development.

After dropping the questions below r=0.7, the CoMac Descriptor™ was revised to a 28-item survey. The resultant 28-item CoMac Descriptor™ was administered in a similar study to 16 new subjects. There was a 74% agreement between CoMac Descriptor™ results and individual interview linguistic analysis as well as 100% agreement on content validity arrived at through inter-rater reliability assessment by content specialists in linguistics and test development.

Thus, our initial testing demonstrated that a brief questionnaire yielded reliable information in three domains known to explain compliance in over 70 per cent of the subjects tested. We concluded that such a questionnaire is useful for individualising the educational approach to initiating or improving self-care adherence behaviours.

For example, persons in the most favourable domains (internal control, high agency and positive emotion) would receive positive reinforcement to continue their successful behaviours. For persons in the least favourable domains (external control, low agency and negative emotions) extensive intervention would be necessary beginning with analysis of the specific negative emotion (e.g. fear, anxiety, depression, etc.). Each of the eight placements would generate actionable approaches most likely to be consistent with the individual's control orientation, agency and emotion.

Control orientation is a strong perception and the least likely of the three domains to be mutable. Nevertheless, the terms the clinician would use in approaching persons with internal or external control orientation would be quite different. For those individuals with an external control orientation, the clinician would couch his or her advice in terms of "Your provider holds the key to your health" or "9 out of 10 persons with diabetes have benefited from taking this medication." In contrast, internal control oriented individuals would receive advice beginning with such statements as "You are in the driver's seat" or "Consider the benefits of this medication -- you may find out that it addresses your health concerns."

For an individual, neither agency nor emotion levels are immutable. Yet, there are a number of studies that report negative emotions, especially depression and anxiety, to be common in chronic disease and lead to low levels of patient compliance with self-care behaviours. Therefore, our approach to patients with negative emotions could take priority over agency until the negative emotions have been addressed. After addressing emotion, the healthcare professional can begin to address low agency; that is, infrequently engaging in self-care behaviours. The healthcare professional can approach persons with internal control, but low agency, by suggesting that they decide on their own what small steps they would take to increase self-care behaviours. For those with low agency and external control, the approach would be for the healthcare provider to suggest a specific small step toward enhancing the ability and confidence of the individual with each step.

Our next step in the development of the CoMac Descriptor™ was to compare the results generated by the CoMac Descriptor™ with the impressions of a clinician actively engaged in the care of the patients being studied. In order to accomplish this we engaged the collaboration of a nurse practitioner caring for the patients with type 2 diabetes in our validation studies. She had extensive experience with these individuals and knowledge of their self-care behaviours. We familiarised the nurse practitioner with the domains being studied and how she might recognise them. Of the 16 patients with diabetes, there was complete concordance between the nurse practitioner's classification of the patients and that derived from the CoMac Descriptor™ in all but three cases. Of the three in which there was not concordance, one did not complete the questionnaire and one was clearly gaming the questionnaire. This study, therefore, assured us that we were dealing with a questionnaire that yielded clinically meaningful and actionable information. Our next developmental step addressed the generalisability of the linguistic approach that we had developed. Specifically: would a modification of the CoMac Descriptor™ directed at hypertension yield comparable results to those seen in diabetes and would such a modification for hypertension in a different culture or language yield comparable results to those seen with the questionnaire in English?

To address these questions we administered a modified CoMac Descriptor™ focused on self-care behaviours in hypertension to over 358 persons with hypertension in English, Spanish, German, and Italian. We then compared results to a widely used questionnaire to predict compliance, the MARS-5. Our a *priori* hypotheses were that those subjects who were internally oriented, and had high agency and positive emotions would be the most compliant, and that those who were externally oriented, and had low agency and negative emotions would be the least compliant. The data generated in this study supported these hypotheses¹¹. Further, we were able to detect differences in the clustering results obtained in different populations with different native languages. While we will need further study to characterise completely intercultural and inter-linguistic issues in our approach, we believe the data generated thus far support our contention that a linguistic approach to predicting self-care behaviours is both reliable and generalisable.

We believe that our linguistic approach yields information that both predicts self-care behaviour and provides avenues or approaches to improve self-care behaviours when such improvement is necessary. First let us begin with two questions: "Does the CoMac Descriptor™ yield information that predicts compliance to self-care behaviour as well as current questionnaires?" and "Does the CoMac Descriptor™ yield information that is more useful and actionable than that provided by current questionnaires?" Table 2 summarises the most common variables used to predict adherence to self-care behaviours. They are demographic and medical/epidemiological in nature.

Table 2: Conventional explanatory variables and descriptive statistics

Age, mean = 52, S.D. = 12

Demographic variables

- Employed: 54%
- \bullet Any college education: 48 %
- Stopped medicine because I got better: 11 %

Medical variables

- Cost of the medication: 6%
- Avoiding side effects: 10%
- \bullet Had severe side effects: 8 %
- Medication not effective: 2%

Data provided by Quintiles/MediGuard

While demographic and medical information is interesting, it is not really useful to the clinician as the variables are not mutable. Table 3 shows the significant variables generated from the study discussed in the previous paragraph. While they give the clinician direction on how he or she might change the regimen, if that seems clinically appropriate, they are not particularly useful in developing an educational approach for the individual patient. The table also shows that the significant variables predicted somewhat over 65 % of the variation.

Table 3: Results for all demographic and medical variables

Correctly classified into an adherence category: 65.24%

Significant variables

- Had severe side effects
- Avoiding side effects
- Employed
- Stopped medicine because I got better

Data provided by Quintiles/MediGuard

Table 4 summarises the results from the CoMac Descriptor™ in the same study. Predictability of compliance was slightly better than for the demographic and medical variables. More importantly, as discussed above, the information provides useful information that the healthcare provider can use in his or her approach to the patient.

Table 4: Results for the linguistic clusters in predicting adherence

Correctly classified when using only linguistic variables: 66.86%

Correctly classified when using all medical, demographic and linguistic variables: 70.37 %

Data provided by Quintiles/MediGuard

We conclude that patients see the world differently and those differences are important both in predicting behaviour and in changing it. For addressing adherence, knowing how patients think is more important than their demographics or attitudes toward their medical regimen. The CoMac

Behaviour Programmes

Descriptor™ provides information on how the patient thinks that is useful to the clinician in the development of an educational approach to improve self-care behaviour and eventually outcomes. We summarise our conclusions in Table 5.

Table 5: CoMac Conclusions

Patients perceive the world differently

For addressing adherence, knowing *how patients think* is more valuable than knowing their demographics and their concerns about medicine

The CoMac Descriptor™ provides what you need to approach the individual patient in a *tailored patient-centric* manner that is consistent with their worldviews

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