Understanding patients' preferences for treatment: the need for innovative methodologies

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Abstract

Treatment selection is now much more consumer driven than in the past. However, there is a need to develop investigative methodological approaches that are sensitive to differences in patient preferences if full account is to be taken of what the patient sees as the best option in terms of different possible treatments available for a particular condition. Previous attitude research has been criticised because it does not provide insight into reasons why people hold different preferences or beliefs. A methodology is described which allows people to describe their concerns and values associated with different treatment options in their own words. This is the repertory grid method of eliciting personal constructs used in conjunction with generalised Procrustes analysis (GPA). An example of the use of this methodology is provided, drawn from research directed towards understanding people's beliefs about genetic technologies. A possible application of the method to understanding treatment preferences related to type 2 diabetes is also discussed. It is concluded that the use of innovative methodologies is essential if our understanding of patient preferences regarding treatment options is to have a significant impact on patient quality of life.

(*Quality in Health Care* 2001;**10**(Suppl I):i50–i54)

Keywords: patient preference; repertory grid method; diabetes

Key messages

- To understand patient preferences for different treatment options, it is important to understand their risk perceptions and beliefs associated with the different treatments available.
- It is also important that these beliefs are described using patients' own words so that they have psychological meaning and are not imposed on the patient by the experimenter.
- The repertory grid methodology is described which will enable researchers to understand individual patient beliefs about the different treatments available in order to optimise treatment selection in accordance with patients' own needs and preferences.

Increased recognition within the healthcare community that treatment selection is now much more consumer driven than in the past means that there is an increased need to develop investigative methodological approaches which are sensitive to differences in patient preferences, and to understand why these differences in preferences exist (see also papers in this supplement by Ryan *et al*,[1] Robinson and Thomson,[2] Lloyd,[3] Montgomery and Fahey,[4] Edwards and Elwyn,[5] and Dudley[6]). Eliciting patient values in a form that can then be used in the development of a treatment regime is not an area of research that has a rigorous methodological foundation, despite the fact that the patients' quality of life can be reduced substantially even by minor side effects[7] which may correlate with individual differences in preferences for different courses of treatment. Appropriate methodologies must be developed to enable these patient preferences to be identified.

As the NHS moves to implement more rigorous systems of clinical governance, and as the new patient advocacy and liaison services promised in *The NHS Plan* are introduced, it will be important that these systems are underpinned by methodologies sufficiently rigorous to command the respect of the medical profession, implying the need to develop new approaches to understanding optimal selection of treatment. The assessment of perceptions, preferences, or other constructs related to attitude using measures must move beyond collecting patient responses to attitude items thought to be important by the experimenters rather than the patients. Experimenter generated attitudinal measures are those thought to be important at the outset of the experiment by the researchers, and they may have little meaning to the patient in psychological terms, although the patient is still required to make a response to these items. The response may, however, reflect a lack of relevance of the measure to an individual or fail to take account of individual differences between participants in the extent to which the item is meaningful in the context in which it is used by the patient.

Many different techniques have been used to inform the development of psychological assessment instruments using beliefs, attitudes, or constructs of importance to respondents rather than what is thought to be important to respondents by researchers. Some, such as focus groups, do not effectively take account of individual differences in beliefs as qualitative data are usually aggregated in the analysis and reporting of results. Other qualitative approaches, such as semi-structured interviewing,[8] are extremely useful when producing

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information for more general level policy decisions but are less useful when examining the measurable associations between events or objects and specific concerns or values held by respondents. Thus, it is often difficult to use extremely unstructured interview data to generate usable results if the aim of the research is to "map out" interlinkages between psychological factors of relevance and patient preferences for a particular treatment from a range of treatment options and combinations (see paper by Ryan *et al*[1] elsewhere in this supplement).

More quantitative approaches use attitude questionnaires, often adopting a survey methodology. Heijs *et al*[9] have criticised earlier attitude research because it does not provide insight into reasons underlying responses to questions. In the case of patient preferences for different approaches to care, for example, it is as important to know *why* patients selected a particular approach as well as which approach they selected. Recent research has adopted conjoint analysis methodology in health care research in an attempt to elicit the factors influencing preferences at the population level.[10 11]

Repertory grid

An alternative methodological solution to such problems is provided by the use of the repertory grid which was originally developed in the area of personality theory,[12] in conjunction with generalised Procrustes analysis (GPA) developed in sensory science.[13] The use of the repertory grid permits respondents to describe their concerns using their own words and focuses responses on the issues under consideration without imposing external experimenter determined characteristics onto the resulting data set.

The advantage of applying the repertory grid method is that individual respondents can determine their own highly personal range of descriptions relevant to the issues under consideration. As many or as few constructs as are relevant to each individual are generated. There is therefore no pressure from the researcher for individual respondents to provide answers to questions that are not relevant or meaningful to their particular case or situation, or which are not psychologically meaningful to them. The data are then used to develop personalised questionnaires which can be analysed using GPA. Unlike other multivariate techniques, respondents do not use a common set of variables to make ratings, and no assumptions are made regarding the underlying determinants of attitude at the outset of the experiment.

A second advantage of the repertory grid compared with traditional interviewing is that maps of consensus agreement linking stimuli are plotted, which can be used to explain why particular risk perceptions or preferences are held by respondents. There is recognition of agreement or disagreement between respondents, and the most important constructs can be identified within the overall data set.

The repertory grid method was developed to provide a means of determining the constructs used by individuals to interpret their environment.[12] The original context centred upon personality traits and involves respondents generating a list of roles and figures believed to be of personal importance to the subject. For each role the respondent is asked to name figures they have known who fit the designated roles. The respondent is then asked by the researcher to consider three specific figures and to consider which two are alike in an important aspect and, at the same time, are different from the third. The way in which two of the figures are alike is called the similarity pole, and the way in which they differ from the third figure is called the contrast pole. For example, the similarity pole might be extraversion, the contrast pole introversion, and the construct dimension extraversion-introversion. The process is then repeated with different combinations of roles until a construct dimension is generated.[12] The method can be applied to contexts other than personality. In essence, it is a way of generating psychological descriptors relevant to the area under investigation and analysing similarities and differences in participant perceptions associated with the descriptors. The approach has been used in many areas including understanding the psychological factors that determine risk perceptions.[14–16]

In the context of understanding patient preferences, the repertory grid method would involve randomly presenting patients with sets of three stimuli—for example, different options for patient care drawn up by healthcare professionals taken from a longer list (perhaps up to 15) of potential options. Patients would then be asked to rank the three stimuli according to some criteria—for example, most preferred and least preferred course of treatment. It is important to note that in all such analyses the "objects" of the context are set by the researchers and the descriptors are chosen by the participants. Hence, in a medical setting it is the health professionals with their expertise who define the treatment options and patients' perceptions of the options are elicited.

To continue the medical scenario, each patient would be presented with perhaps 10 different combinations of randomly selected triads of stimuli. The patient would then explain why he or she ranked the stimuli in this particular order. This process would be repeated until all of the potential treatments had been evaluated in this way. The resulting qualitative data would then be analysed using quantitative methodologies used in conjunction with interobserver reliability techniques in order to determine important reasons why a particular course of treatment might be preferred over another.

The resulting information is used to develop a personalised questionnaire for each patient. Patients would then be asked to rate different treatments according to the constructs they themselves have generated in the repertory grid method. The entire data set would then be

subjected to GPA. GPA is a statistical algorithm for determining a consensus from a multidimensional configuration of points. The repertory grid method produces a matrix of scores from one individual who has assessed a number of stimuli—for example, different treatment options—against a set of personal constructs—for example, risk perceptions, preferences and concerns about different treatment options. GPA allows each individual to have a unique set of attributes by transforming the resulting data (by translation, rotation, or reflection) in order to find agreement or consensus among respondents. The consensus represents the average of all the transformed configurations, and interpretation of this consensus enables those constructs of greatest importance to be identified. The application of GPA results in a graphical representation of the type of treatment in several dimensions, each new dimension incorporating psychological constructs of importance from all of the individuals interviewed, and is a particularly useful method when information is required about how individuals differ and to what extent they agree in their perceptions of the same stimulus.[17] The methodology does not require a large sample size in terms of patient recruitment, which may prove advantageous although, of course, the results can be validated in larger sample sizes using more traditional factor analytical techniques.[14 15]

Case study: genetic modification

To demonstrate the use of this type of approach, an example is provided by research designed to understand public concerns about different applications of genetic modification (fig 1). In this example the aim of the research was to understand what is driving public concerns about different applications of genetic engineering without making a priori assumptions about what the public is likely to consider important. The research identified psychological constructs that shaped public perceptions using the repertory grid methodology that allowed investigation and understanding of the most salient issues associated with genetic technologies to be examined. Prior to this empirical work, much of the research examining public attitudes towards genetic engineering had involved researcher defined constructs.[18] Other research has assumed that risk perceptions associated with genetic engineering will be determined by the same underpinning psychological factors as those that define more global risk domains.[19] In this example the repertory grid method was used to understand the psychological constructs underlying attitudes towards various applications of genetic engineering drawn from medical, food, and agriculture related areas in order to determine possible technology acceptance problems.

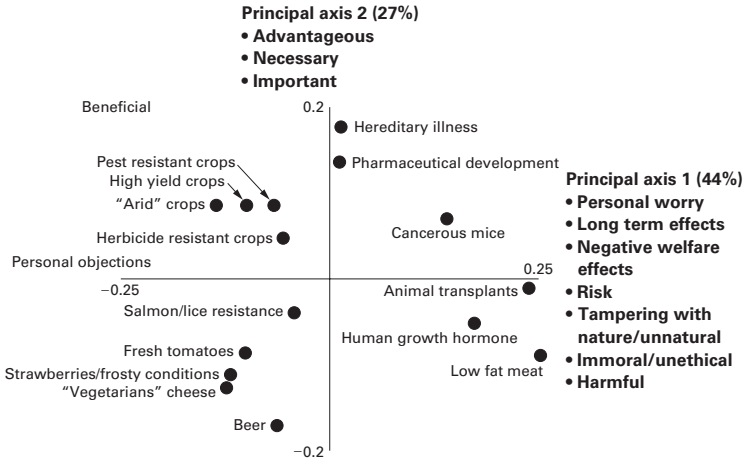

Figure 1 Graphical representation of people's beliefs about different applications of genetic modification (1st and 2nd axes of the GPA group average configurations) following identification of these beliefs through the use of the repertory grid method. Percentage values refer to variance explained in the analysis. Adapted from Frewer et al.[14]

Twenty five respondents took part in the repertory grid interviews. They were asked about 15 different applications drawn from the different areas of genetic engineering. The repertory grid was divided into two phases; in the first phase constructs describing concerns about the different applications of genetic engineering were elicited from respondents, and in the second phase the respondents rated each of the applications on each construct they had decided were relevant to them personally.

In the first phase all respondents were given a questionnaire with the applications of genetic engineering presented in groups of three on separate pages. Each questionnaire was individually constructed with the triadic combinations being presented in random combination within and between questionnaires. Each application was presented twice within the questionnaire to give 10 different combinations of stimuli in total. For each triad, respondents were asked "Which of these applications of genetic engineering gives you the most concern and why?" and "Which of these applications gives you the least concern and why?" The respondents then listed the reasons or constructs that they used to rank the different applications of genetic engineering. A personalised questionnaire was created for each respondent which used the same language as each individual had used to describe his or her beliefs about genetic engineering application. Each application was scored on bipolar line scales on each construct of importance to each respondent; personalised labelled end points derived from the repertory grid were used to develop the scales. The data were then subjected to GPA and the resulting diagram illustrated the relative positions of the applications. In the example illustrated in fig 1 a group average was calculated, although individual diagrams of "perceptual space" illustrating how the different concerns are important to individual respondents can also be understood relative to the different applications.

In fig 1 the important psychological constructs are identified in bold against the axis for which they have explanatory value. The results indicate that applications involving animals and human genetic material were viewed very negatively compared with those involving other types of organisms. However, the use of gene technology in the treatment of hereditary

illness and development of novel pharmaceuticals was also seen to be advantageous, necessary, and important.

Application of repertory grid to patients

A similar methodology can be used to assess patient preferences for different approaches to treatment. The reasons for expressing preferences—for example, patient risk perceptions and concerns—can be used to label the different dimensions, and the different treatments can be mapped out against these concerns. Once the factors which drive patient concerns and preferences are understood, individual preferences for treatment can be analysed using a questionnaire derived from the analysis, and the best treatment selected according to expressed patient needs.

This approach might be used, for example, in the context of the care of diabetic patients. While it is recognised that each illness has its own unique contextual framework, the treatment of diabetes raises important issues regarding patient centred care.[20 21] Physicians and dieticians can prescribe insulin, drugs and suggest dietary regimes but it is the patient who has to fit these activities into his/her daily life. There is currently no cure for diabetes so sufferers have to manage their condition every day of their lives. For those with type 1 diabetes, which often manifests itself in childhood, this means a lifetime of self-management. Type 2 diabetes often develops late in life which means that sufferers have to make major lifestyle adjustments to well established habits. Despite the serious health risks involved, many patients find it extremely difficult to follow the indicated medical regime to control their diabetes, which implies that there is a need to take into account individual differences in treatment preferences.[22]

However, in order for this to occur, values and preferences associated with different treatment approaches must be understood. There are many different ways of managing diabetes; if a patient struggles to achieve satisfactory diabetic control with one approach, it may be that some aspect of that approach is inappropriate for that individual. The treatment "imposed" on the patient may create conflicts with other priorities in the person's life which may best be dealt with by changing the recommendations made without necessarily compromising the level of diabetes control that can be achieved. Some of the different strategies possible for the treatment of type 2 diabetes are:

(1) dietary management including recipes, diet counters, nutritional therapy;
(2) behavioural counselling using different approaches and theoretical frameworks (for example, education/information based, stages of change, psychodynamic approaches, systems theory);
(3) weight management;
(4) stress management;
(5) blood glucose awareness training;
(6) different classes of drugs (sulphonlyureas, biguanides, glucosidase inhibitors, thiazolidinedione) with different advantages and side effects[23];
(7) insulin treatment, including different forms of insulin.

These alternatives can also be used in combination—for example, different drugs can be used in conjunction with different dietary regimes. Insulin injections allow greater flexibility of timing and content of meals while maintaining glycaemic control, but might be unacceptable to a patient for other reasons such as fear of self-injection. This might suit people who do not mind injections and do not want to make major lifestyle changes. However, if the best treatment option is to be offered, it is important to take account of patient preferences regarding different treatments.

Patients need to be informed of the strengths and weaknesses of the various options so that they can make choices more appropriate to their lifestyle. In order to understand how values and perceptions map onto patient preferences for different treatments, it is important that the nature of these preferences is understood. The use of the repertory grid method would allow understanding of the perceived advantages and disadvantages of treatments, facilitating the identification of the most appropriate treatment for a patient faced with a particular set of personal circumstances. Such research would enable patients to express their concerns in their own words and not have belief systems or values imposed externally on them by the experimenter—that is, techniques such as the repertory grid method will help practitioners to understand which treatments are most suitable for patients from the point of view of patient preference as well as from a purely clinical perspective.

Conclusions

The traditional "top down" approach to understanding how best to treat patients is no longer regarded as appropriate. However, at present there is a problem with identifying methodological approaches which take account of both the need for patients to express preferences and concerns regarding treatment options using their own terminology, and the considerable intra-individual variation in treatment preferences which may explain why some treatments are successful for some patients but not for others. The use of techniques such as the repertory grid provides a useful starting point for understanding patient preferences for particular treatment approaches and integrating knowledge about these processes into health policy decision making.

1 Ryan M, Bate A, Eastmond CJ, *et al.* Use of discrete choice experiments to elicit preferences. *Quality in Health Care* 2001;**10**(Suppl I):i55–60.
2 Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *Quality in Health Care* 2001;**10**(Suppl I):i34–8.
3 Lloyd AJ. The extent of patients' understanding of the risk of treatments. *Quality in Health Care* 2001;**10**(Suppl I):i14–18.
4 Montgomery AA, Fahey T. How do patients' treatment preferences compare with those of clinicians? *Quality in Health Care* 2001;**10**(Suppl I):i39–43.
5 Edwards A, Elwyn G. Understanding risk and lessons for clinical risk communication about treatment preferences. *Quality in Health Care* 2001;**10**(Suppl I):i9–13.
6 Dudley N. Importance of risk communication and decision making in cardiovascular conditions in older patients: a

discussion paper. *Quality in Health Care* 2001;**10**(Suppl I):i19–22.
7 Lancaster TR, Singer DE, Sheehan MA, *et al*. The impact of long-term warfarin therapy on quality of life. *Arch Intern Med* 1996;**156**:1829–36.
8 Miles S, Rowe G. The use of the laddering method in social science research. In: Breakwell G, ed. *Doing social psychology*. British Psychological Society Publications, 2001 (in press).
9 Heijs WJM, Midden CJH, Drabbe RAJ. *Biotechnology: attitudes and influencing factors*. Eindhoven: Eindhoven University of Technology. 1993.
10 Ryan M, Hughes J. Using conjoint analysis to assess women's preferences for miscarriage management. *Health Econ* 1997;**6**:261–73.
11 Ryan M. *Using consumer preferences in health care decision making. The application of conjoint analysis*. London: Office of Health Economics, 1996.
12 Kelly GA. *The psychology of personal constructs: a theory of personality*. New York: Norton, 1955.
13 Dijkerhuis GB, Gower JC. The interpretation of generalized Procrustes analysis and allied methods. *Food Quality and Preference* 1991;**3**:67–87.
14 Frewer LJ, Howard C, Shepherd R. Public concerns about general and specific applications of genetic engineering: risk, benefit and ethics. *Science, Technology and Human Values* 1997;**22**:98–124.
15 Frewer LJ, Howard C, Hedderley D, *et al*. What determines trust in information about food-related risks? Underlying psychological constructs. *Risk Analysis* 1996;**16**:473–86.
16 Saba A, Moles A, Frewer LJ. Public concerns about general and specific applications of genetic engineering: a comparative study between the UK and Italy. *J Nutr Food Sci* 1998;**28**:1, 19–29.
17 Gower JC. Generalized Procrustes analysis. *Psychometrica* 1975;**40**:33–42.
18 Zechendorf B. What the public thinks about bio/technology. *BioTechnology* 1994;**12**:870–5.
19 Frewer LJ, Shepherd R, Sparks P. Biotechnology and food production: knowledge and perceived risk. *Br Food J* 1994; **96**:26–33.
20 Williamson AR, Hunt AE, Pope JF, *et al*. Recommendations of dietitians for overcoming barriers to dietary adherence in individuals with diabetes. *Diabetes Educ* 2000;**26**:272–8.
21 Tillotson LM, Smith MS. Locus of control, social support and adherence to the diabetes regimen. *Diabetes Educ* 1996;**22**:133–9.
22 Bradley C, Pierce MB, Hendrieck C, *et al*. Diabetes mellitus. In: Johnson M, Johnson DW, eds. *Comprehensive clinical psychology*. Oxford: Pergamon Press, 1998: 277–304.
23 Lipkin E. New strategies for the treatment of type 2 diabetes. *J Am Diabetes Soc* 1999;**99**:329–34.