What Outcomes Are Important to Patients with Long Term Conditions? A Discrete Choice Experiment

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ABSTRACT

Objective: To assess how much patients with long-term conditions value self-efficacy (i.e., confidence in their ability to manage their condition) compared with other health outcomes, including measures of quality of life, and process outcomes including access to General Practitioners.
Methods: Discrete Choice Experiment (DCE) set in UK community settings. Participants: 367 patients (mean age 57.5) living in the community with a wide range of self-defined long-term conditions. Main outcome measures: the relative value that individuals place on four specific outcomes, namely, self-efficacy, Health Related Quality of Life (HRQoL), access to General Practitioners, and level of isolation.
Results: Most responders completed their questionnaire in a consistent manner. Most valuations of outcomes were in the expected direction and were statistically significant. A substantial minority of responders exhibited counter-intuitive preferences. The existence of a significant constant in all models raised concerns about model misspecification. Nevertheless, all models showed that participants were willing to trade substantial reductions in their HRQoL for improvements in their self-efficacy.
Conclusions: The majority of patients with chronic conditions were able to complete the DCE questionnaires. However, the existence of counter-intuitive preferences and evidence of model misspecification require further investigation. These issues are largely overlooked in the health economics literature. Self-efficacy is an important outcome for this group and is not included explicitly in conventional HRQoL measures. This is potentially important where decisions are made on the basis of cost-effectiveness using Quality Adjusted Life Years as the metric. Exclusion of these outcomes may lead to the cost-effectiveness of these interventions being understated.
Keywords: Discrete Choice Experiment, health economics, Quality Adjusted Life-Years, quality of life.

Introduction

Recent policy has targeted self-care as a means to improve patient outcomes and reduce costs [1,2]. Self-care has been defined as care taken by individuals toward their own health and well-being [2]. Interventions have been designed that support individuals' ability to self-care, for example, the Expert Patient Programme (EPP) based on the chronic disease self-management program developed in the United States by Lorig [3,4]. The "EPP" aims to provide self-care support to any individual with a chronic condition in England and is a generic, lay led, group program involving six-weekly sessions. The EPP is designed to enable participants to develop appropriate self-care skills including patient's "self-efficacy" [5]. The concept of self-efficacy refers to a psychological state which relates to an individual's confidence that they can achieve some task (such as managing the symptoms of their disorder or engage in regular exercise) [6–8], and is one of the most important concepts in modern psychological approaches to understanding health behavior [9]. Self-efficacy is increasingly accepted as a mediating variable and an outcome of self-management programs but this has become normative without evidence of what patients most value in managing long-term conditions.

A recent trial [5] demonstrated that a UK version of the chronic disease self-management program was effective at improving self-efficacy, and a cost-effectiveness analysis based on the same clinical trial [10] generated Quality Adjusted Life-Year (QALY) gains for these interventions using the EQ5D instrument. The EQ5D instrument measures Health Related Quality of Life (HRQoL),

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across five dimensions, namely mobility, ability to self-care, ability to perform usual activities, level of pain/discomfort, and level of anxiety/depression. The cost-effectiveness analysis concluded that the EPP intervention was likely to provide a cost-effective alternative to usual care in people with long-term conditions at commonly used threshold values of a QALY.

Thus QALYs, often generated from EQ5D, have a commonly expressed value [11] but they may not incorporate all the outcomes that are of interest. In contrast, while self-efficacy is undoubtedly an outcome of interest (at least for practitioners and researchers), we have no knowledge of whether self-efficacy is "of value" per se, or indeed what that value might be. This leads to problems of interpretation as decision-makers cannot assess the relative merits of self-efficacy compared with HRQoL. In the example above, the EPP was deemed to be likely to be cost-effective based solely on the QALY, although there was a large degree of uncertainty around the decision. Valuing self-efficacy (or other relevant outcomes) in terms of QALYs gives decision-makers additional information and can be incorporated into the cost-effectiveness analysis and could reduce the uncertainty around a decision.

Discrete Choice experiments (DCEs) are one method of either expanding the measure of outcome or incorporating factors other than health outcomes [12]. DCEs are based on the premise that the benefits associated with health-care interventions can be expressed in terms of the "attributes or characteristics" of that intervention [13] and the "attributes or characteristics" of the person valuing them [14,15].

Process outcomes may be important in the evaluation of health-care technologies, and DCE enables the relative values of these outcomes to be assessed [12]. For example, speed of access to health care, who provides that health care and where it is provided, are often considered as important aspects of health care that may not be captured by a measure of HRQoL [12].

DCEs have been used frequently in the health economics literature to estimate preferences in miscarriage management [16], management of prostate cancer [17], as well as in a variety of other conditions and in numerous settings [18–29]. However, DCEs have not been previously employed to investigate the trade-off between HRQoL, psychological outcome measures such as self-efficacy, and social outcomes such as isolation and/or process outcomes such as General Practitioner (GP) access. One advantage of the DCE methodology is that it enables the individual to simultaneously compare and value a number of different attributes. This may have the added benefit of limiting the "salience" problem identified with standard gamble techniques, where there is discordance between stated preferences and actual choices because of the experiment focusing the individuals' concentration on one specific attribute [30], although it is acknowledged that responders may still not focus on the true opportunity cost of their choice [31].

This article describes a DCE conducted to examine the relationship between HRQoL and other outcomes which may be of relevance to patients with long-term conditions. In addition, the estimation of rates of substitution between the QALY and self-efficacy enables decision-makers to include these outcomes in their assessment of cost-effectiveness.

Methods

The authors conducted a DCE: a questionnaire based stated choice method, to explore the outcomes that are most valued by patients. There are several recognized steps for conducting a DCE [32,33], described below.

Defining Attributes/Outcomes

Qualitative interviews and focus groups carried out alongside a Randomised Controlled Trial of the EPP identified isolation and access to health professionals as a major influence on individual well-being [34]. In addition a systematic review of the published economic evaluation literature identified self-efficacy as an important outcome that patients valued [35]. The attributes and their levels were chosen to be plausible for the responders to answer [32].

Based on these sources, three outcomes were selected for inclusion into the study and access to GPs, level of social isolation and level of self-efficacy (patients' confidence in their ability to manage their condition). In addition, because the rationale of the study was to assess the importance of self-efficacy and the other outcomes relative to HRQoL and examine whether such outcomes could be included in cost-effectiveness analysis, a measure of HRQoL was included. As it is frequently used in economic evaluation and has previously been used in DCEs [36,37], the EQ5D was used as the basis for measuring HRQoL. EQ5D measures patient health status across five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with three possible responses (no problems, moderate problems, or severe problems) for each dimension. This locates each participant into one of 243 mutually exclusive health states. Clearly, including this number of levels of an attribute is impractical. Three states were selected as levels for this attribute to maintain the statistical efficiency of the experiment. The three states showed a clear ranking between them and were all levels that were considered plausible for this patient group [32] and that they were likely to have experienced.

The use of "psychological" outcomes in DCEs, such as self-efficacy, is potentially limited by the interpretation responders place on them. It could be argued that these outcomes depend on

emotional state of the individual or could be merely acting as surrogates for other outcomes (such as HRQoL). However, evidence from the pilot study suggests that this may not be a major problem in this study. It should also be noted that these problems are not unique to this DCE, or DCEs in general. Indeed, similar issues of interpretation have been identified with "objective" measures of health status such as the SF36 [38,39]. The generalized Linear Latent and mixed models (GLLAMM) model described below also allows valuations of attributes from different groups with systematically different values. This model estimates that the proportion of individuals in each "latent class," and allows the preferences of these different classes to be estimated.

The endogeneity of this measure is also a potential problem. Ideally, it may be better to describe objective outcomes (such as a health state) and derive values for this health state from individuals rather than asking them to value a subjective health state such as confidence. While this is a limitation of the study, the policy aim was to establish the value of self-efficacy (or isolation or GP access) relative to HRQoL. This is an important policy question as the EPP was purchased and rolled out based on the results of experiments showing improvements in self-efficacy. Self-efficacy could be considered an important outcome in its own right, not just as a surrogate for future improved health.

To improve the statistical efficiency of the experiment (that is to enhance the power of the study to detect the impact of moving between levels of attributes), the number of levels in each attribute should be multiples of each other [40]. That is if we have four attributes, we could have three with four levels and one with two levels, or even one with eight levels. We should not, however, have some attributes with two levels and others with three. The practical implication for this DCE was that there should be four attributes each with three levels (as having three levels for each clearly satisfies the above requirement). Having more than three levels for each attribute increases the number of questions responders is asked and therefore increases the cognitive burden considerably.

Not only is this design statistically efficient, but it also enables some two-way interactions terms to be examined in a longer version of the questionnaire described below. These interaction terms are typically ignored in DCEs in the health economics field.

The attributes and levels identified from this process are presented in Table 1.

Short and Long Questionnaires

Two questionnaires were developed. Both questionnaires used the same attributes with identical levels; however, the number of questions differed. The shorter questionnaire contained 10 questions (8 unique questions and 1 repeated question), while the longer questionnaire contained 28 questions (26 unique and 1 repeated). This allowed us to test whether questionnaire length (and therefore cognitive burden) impacted on response rate. In addition, the longer questionnaire enables the inclusion of interaction terms in the model. Interaction effects are ignored in most DCEs in the health economics literature as they add to complexity and to the cognitive burden for respondents. In this DCE the possibility that there were "interactions" between the attributes described in the DCE was explored. For example, being in a bad health state may reduce an individuals' utility by 0.2 and having low levels of confidence may reduce utility reduces by 0.1. However, having both bad health and low confidence may result in a drop of utility greater than 0.3.

The main results section presents results where the responses to short and long questionnaires were pooled, so that both