

Supplementary Material

Detail of Included Studies

Among the 4 studies focusing on eliciting patient preference in a disease specific context, one looked at measuring patient preference among women attending prenatal class preparing for a caesarian section delivery.(23) The study aimed to determine patients' priorities and preferences for importance of specific intra-operative and post-operative anesthesia outcomes. The research team created simple descriptions to reflect a number of symptoms focused around a particular outcome (derived from a list obtained from a MEDLINE search for anesthesia outcomes).

Women were asked to rank the importance of these outcomes using both priority ranking and relative value scales. Patients were given detailed written instructions to measure ranking: "distribute \$100 such that the more money you spend on a condition, the less likely it will occur." The study concluded that pain during and after caesarian delivery was the greatest concern followed by vomiting and nausea.

Another study measured patient behavioural goals in the context of physical therapy using a patient goal priority questionnaire.(22) The PGPQ tool is a behavioural goal assessment tool in which patients with chronic pain rank everyday life activities affected by pain and their most important goals for physical therapy treatment. The study's objective was to measure the test-retest reliability of the patient goal priority questionnaire (PGPQ) and also chance-agreement between the PGPQ and a therapist guided tool called the patient goal priority list (PGPL). The study found moderate test retest reliability of the PGPQ tool (correlation coefficients .35 to .81) and there was little agreement between chance-corrected analysis of PGPQ and PGPL at two time points ($\kappa = .46$ [95% CI = -.24 - .68]) for the top priority recorded in each tool. Overall,

the study did not create outcome measures for patient preference-related concepts, but rather measured the validity of the PGPQ tool.

The value of Adaptive Conjoint Analysis (ACA) was studied in an article assessing patient relevant priorities and preferences for specific cytotoxic medications in lupus nephritis.⁽²⁵⁾ Specifically the study measured relative priorities and preferences for patients and the percentage of women preferring cyclophosphamide (risk of premature ovarian failure and hemorrhagic cystitis) over azathioprine (long term decrease in renal function). ACA is a tool used to determine the attributes of a particular product or service that individuals value most. The objective being to determine what combination of attributes most influences decision making. ACA was used in this study to change the probability of renal survival or risk of major toxic effects to see how these attributes affected preference. In summary the study concluded that ACA was a feasible method of assessing preference. Using ACA the study concluded that of the nine medication characteristics studied, risk of infection had the greatest impact on preference and that pre-menopausal women were more likely to choose cyclophosphamide compared with their counterparts (56% vs 80%).

The last of the four (23-27) context specific studies measured patient preference for use of vitamin K antagonists compared to direct oral anticoagulants in atrial fibrillation. The study developed a 7 item Likert scale questionnaire eliciting preference for continuing current anticoagulant versus preference to switch to another anticoagulant. The study closely tied patient preference to medication adherence and aimed to develop a tool for clinicians to implement in primary care in order to document preference for anticoagulant treatment.

Table S1: Quality of reporting in included papers (STROBE checklist)

Criteria	Asenlof P. 2009	Carvalho B. 2005	Dierckx K. 2013	Fraenkel L. 2001	Zolfaghari S. 2013	Fried T. 2011
Study Design	Prospective cohort	Study design was unclear.	Cross sectional	Study design unclear – appears cross sectional.	Study's design was stated but the methodology was ambiguous (case control study without a control group).	Cohort
Did the study provide clear eligibility criteria and the sources and methods of selection of participants?	Yes	No, a source of recruiting participants was discussed but there was no clear study population defined	Yes	Yes	Yes	Yes
Was the selection robust or biased?	Biased, did not include patients with cancer, inflammatory or neurological diagnosis. Swedish language skills were also required.	Biased, only included pregnant women going to prenatal classes for cesarian section. Most women were of similar age, highly educated, and of high socioeconomic status.	Biased sample, only included physical therapists who spoke Dutch and worked in a self-employed setting. Patients were also dutch speaking and patients with psychiatric or CNS disorders were excluded.	Biased, recruited younger women specifically. The sample was also applicable only to rheumatology practices.	Biased sample excluding people with severe diseases, impaired cognitive function, age <18 and inability to understand German.	Robust, the groups of patients studied did not differ significantly according to age, gender or number of chronic conditions.
Were all outcome measures clearly defined?	Yes	Yes	Yes	Yes	Yes	Yes
Were all potential biases clearly stated?	Yes	Yes	Yes	Yes	Yes	No
Were any efforts to address potential bias described?	Yes	No	Yes	No	No	No
Was the study size reasonable?	Yes	Yes	Yes	Yes	Yes	Yes
Were there appropriate statistical methods used?	Yes	Yes	Yes	Yes	Yes	Yes
Was descriptive data of study participants (eg demographic, clinical, social) provided?	Yes	Yes	Yes	Yes	Yes	Yes
Reported numbers of outcome events or summary measures?	Yes	Yes	Yes	Yes	Yes	Yes
Did the study provide source of funding and the role of funders for the present study?	Yes	No	No	Yes	No	Yes

Incorporation of priorities and preferences into the electronic medical record.

Integrating patient preferences into the longitudinal electronic clinical records provides information not only for clinical decision making but also provides information to focus policymakers and quality assessment on patient centred care, as well as information for researchers looking to explore variations in values patients place on clinical outcomes. The discussion paper by Ruland C, 2001 et al.¹⁰, highlighted three aspects of the elicitation of patient preferences prior to incorporation into electronic medical records that are important considerations:

- (1) Integration of patient preference related concepts into electronic medical records requires standardized communication (forms and tools) between professionals
- (2) As we found in this systematic review, there is a paucity of appropriate tools generalizable to all disease states and multi-morbidity
- (3) There is no standardized representation of preference-related concepts and terminology to a computer-based system.

Aspects of Other Tools of Potential Relevance

Dierckx K. et al. (2013)²² looked at the degree to which shared decision making (SDM) occurred in physical therapy with a focus on whether patients' preferred level of involvement agreed with the therapist perception of patient preferred level of involvement. The study measured locus of control rather than measuring individual patient preferences for care. Locus of control was evaluated using the Control Preference Scale (CPS) which was a Likert scale responding to questions relating to preferred level of control in treatment decision making (from 0 to 4 ranging from "no control" to "maximum preferred control"). Interactions between patient and therapist during consultations was measured for patient involvement during decision-making process with

the OPTION instrument. The study concluded that low level of patient involvement was evident with providers often acting paternalistically. Of interest, in 64% of cases the patient preferred to be more active in involvement in decision making than the physical therapist had perceived they would like to be.

Methods for Eliciting Patient Preferences

Ruland C, 2002 et al.¹⁰, provides an excellent discussion of methods used for preference elicitation and the underlying patient preference concepts. Overall there are four theoretical methods underpinning tools that may be used to elicit patient preferences. Tools for cost utility analysis would be too complicated for clinical care. Standard Gamble (SG) is a tool which is based on utility theory (economic theory that holds the belief that a service's utility is a measure of satisfaction that the consumer derives from using the service) which states that while it is impossible to measure utility derived from a particular service or product, it is possible to rank alternatives in order of preference. For example, a utility of 0.5 in SG represents the maximum probability of death a person is willing to accept in a gamble to obtain perfect health rather than living with the described health status.

Time Trade-Off (TTO) is also based on utility theory but in the case of TTO (in relation to healthcare) a utility value of 0.5 expresses the proportion of the remaining life living with the describe disease or health a person is willing to give up for perfect health.

Thirdly, Visual Analogue Scales (VAS) act as a psychometric measure of eliciting value functions. More specifically, a utility measure of 0.5 on VAS represents the value a person places on his current health state in relation to the low and high anchors on the scale. VAS can be used to directly compare priorities among various treatment decisions and measures of priority

are in relation to rankings along the scale. Test retest validity is also easy to measure in VAS scales as it is based on agreement in both rank order and also numerical positions on the analogue scale.

Adaptive Conjoint Analysis (ACA) is an established method of eliciting consumer preferences in market research and is increasingly being used in healthcare for eliciting patient preferences.

ACA in the case of treatment preferences operates on three major assumptions: (1) Each treatment option can be broken down into separate attributes (specific characteristics of the treatment option such as efficacy or adverse events) and each attribute can be defined by certain levels or degrees of outcome. (2) Respondents have unique values and utilities for each attribute and differences in these characteristics allows investigators to determine what features drive patient choice. (3) Utilities can be summated across attributes to identify particular values or utilities that patients value for one treatment over another.

ACA offers the advantage of introducing a wide array of attributes to the patient without risking information overload or respondent fatigue which may be common in other tools used to elicit detailed patient preferences. ACA includes minimal interview bias and ensures that all attributes under consideration are evaluated in a comprehensive manner. A disadvantage of ACA is that it is difficult to perform on an individual patient basis, may be more suitable to specific contexts or single diseases and is time consuming. Therefore, ACA may be more useful in eliciting group preference but less applicable to determining individual preferences for care.