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Background Paper

Qualitative outcome assessment and research on chronic disease management in general practice. Highlights from a keynote lecture, EGPRN May 2011, Nice

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KEY MESSAGE:

- Categorization of patients with a chronic disease according to qualitative outcome assessments, offers the opportunity for general practice to engage in research that seeks to understand patients as they make their future, and to understand the impact of clinical interventions on this process

ABSTRACT
At its 2011 conference in Nice, France, the European General Practice Research Network (EGPRN), considered the issue of Relevant Outcome Measures in General Practice Research into Chronic Diseases. This paper, which is adapted from a keynote lecture given during that conference, considers the role of qualitative outcome assessments in research. Such assessments have a great deal in common with the patient-centred approach of general practice as they can capture the overall state of a patient rather than capturing only certain aspects. Research suggests that patients can be categorized, based on qualitative outcome assessment, and over time might change category. This approach to assessment brings to our attention alternative ways of considering the future: future as currently being made or future as predictable, at least to some extent. Although general practice needs the evidence from research that predicts the future, it also needs to engage in research that seeks to understand patients as they make their future, and to understand the impact of clinical interventions on this process.

Key words: General practice/family medicine, general; integrated care; qualitative designs and methods

Members of the European General Practice Research Network (EGPRN), at their 2011 conference in Nice, France, considered the issue of Relevant Outcome Measures in General Practice Research into Chronic Diseases. This keynote lecture considers the role of qualitative assessments in research. Such assessments have a great deal in common with the patient centred approach of general practice as they can capture the overall state of a patient rather than capturing only certain aspects. Research suggests that patients can be categorized, based on qualitative assessment, and over time might change category. However, the role of qualitative assessment in research that is able to predict the likelihood of an outcome in medicine is less clear.

PATIENT CENTRED MEDICINE

Patient centred medicine has become established within General Practice (1). Taking account of the whole person including their relationships and the environment in which they live, is an important aspect of this approach (2). This is perhaps particularly so in the management of chronic disease. Our patients live with their chronic disease through all the changes of life—getting older, changing jobs, gaining and loosing close relationships, economic upturns and downturns and of course change in their chronic disease. This experience shapes them as people and influences how they live with their disease.

CHALLENGES IN OUTCOME ASSESSMENT OF CHRONIC DISEASES

General Practice draws on evidence and research methodology from many scientific disciplines. However, a specific methodological contribution that general practice might make arises from its understanding of the individual as a whole, based on experience of patient-centred medicine. This contribution might take the

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form of developing and implementing the use of health outcome assessments that come close to the ideal of taking account of the whole person. Such assessments would need to include how the patients are relating to the people around them and their environment as well as assessment of their current physical and mental state, and the influence of past and future (3).

There are of course many questionnaires used in population studies, which assess people across multiple dimensions of their general health or quality of life, and their use has become common in studies evaluating interventions. Such scales include the SF36, which is often used alongside disease or symptom specific measures (4). However, there is not yet a standard approach to the use of general health and quality of life measures, and in trials their main use is to detect unforeseen effects (5). Similar in nature but focusing on a different dimension of life from that of disease, are population measures of wellbeing (6).

Symptom or disease specific measures are usually used as the main outcome for evaluating interventions. These may be clinical measures such as HbA1c as a measure of diabetes control, or a patient reported outcome assessing, for example, pain or function. Experience of undertaking qualitative interviews related to clinical trials, suggests individuals can change qualitatively with no change in their patient reported outcome score (7–9). They become recognizably different or transformed, yet run the same HbA1c or have the same level of pain or dysfunction. For example, individuals might feel frustrated with their back pain, floundering around trying things, yet unable to move forward. Six months or a year later they can transform to being calm and resigned to their back pain, but this change is not necessarily reflected in their pain or function score. Such a transformation may not be noticed by the individual as it occurs gradually, but is apparent on analysis of a second interview (9).

QUALITATIVE OUTCOME ASSESSMENTS

One could argue that we just need better measures, across enough dimensions to be able to capture as a score the state of individuals in an overall, qualitative sense. However, this might not be possible as there are so many different factors influencing the individual, and all these factors interact with each other. Influences on an individual also have their effect over many different timescales. For example, there are long-term influences from early in life and short-term influences day-to-day or hour-to-hour. With so much interaction we may need to assess what emerges, that is the overall state of the individual that cannot be captured through assessing component parts. Such a qualitative assessment may relate to a particular health issue but captures the overall state of the person. Through comparison, it is possible to develop categories of these qualitative assessments. Although the boundaries between categories are often indistinct, the categories have a recognizable character and may have utility.

There are a number of examples of qualitative assessment. For example, based on self management strategies, qualitative categories of people living with type 2 diabetes have been developed: those who adapt their lives whilst striving for compliance with health professionals' recommendations, those who adapt their diabetes management to suit their lives and those unable to find any sustained management strategy (10,11). Similarly, people living with back pain have been categorized into those that those that believe that pain and activity are harmful and those that do not (12). People with severe back pain have been categorized as those who perceive their pain as taking them over, and those who come to terms with their pain (13). Such categories are not hierarchical—there need be no implicit assumption of one being in some way better or worse than another, as there is with a scale.

Within General Practice, such categories might be useful for recognizing the overall state of a patient, which is then taken into account for treatment decisions. For example, advice can be tailored to the management style of the patient; where appropriate attention can be given to the psychological aspects of living with pain. In these examples, the categories are capturing just one aspect of the overall state of the individual, all be it an important aspect. A more generic categorization, for example based on the pattern of change or non-change of patients in an overall sense, could be used and applied to diverse chronic diseases and people living with more than one chronic disease (3,9). Assessing people based on the emergent pattern of change, that is how they adapt and adjust (or not) in the current phase of their illness, comes closer to assessing the whole person as these patterns are the result of the many influences shaping the person from across time.

SHARED DECISION MAKING: LOOKING AHEAD

For making decisions about the management of chronic disease, patients and clinicians often seek some degree of prediction of the future to guide their decisions—what is likely to happen and what difference will treatment make? Although difficult to apply to individuals, research evidence available to inform these decisions is produced at a population level, where an intervention is shown to make a difference to a predicted health outcome. For themselves as individuals, the notion of health outcome makes little sense to patients as they continue to live through time with chronic illness (7). They can however describe how they are in their current state and what influences this (3). Such a qualitative assessment may not have a role in predicting the future, but it might have a role as an assessment of how a patient is currently making the future (14). This might suggest why an intervention is working or not for certain categories of patients. Whether we can then say from this that an intervention is likely to work or not, for certain categories of future patients, needs further research.

Conclusion

Qualitative assessments provide a way of capturing the current overall state of a patient that is close to the type of assessment used in patient centred general practice. This approach to assessment brings to our attention alternative ways of considering the future: future as currently being made or future as predictable, at least to some extent. Although general practice needs the evidence from research that predicts the future, it also needs to engage in research that seeks to understand patients as they make their future, and to understand the impact of clinical interventions on this process.

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