

Involving the 'consumer' in the evaluation of dental care: a philosophy in search of data

T. Newton¹

Recent initiatives by the government of the United Kingdom have led to an increasing interest in patient and public participation in the evaluation and design of healthcare.^{1, 2} To date this has largely concentrated on the identification of the views of service users of both the treatment they have received, and of what could be called the structural dimensions of service provision, for example ease of access, waiting times, availability of treatment facilities, priorities in care and so on.^{3, 4} In this article I shall explore three broad questions: Who counts as a 'consumer' and what do we want to know from them? How do we go about ascertaining their views? How do we use information on the views of consumers in planning services and providing care?

I will argue that we should involve a broader range of individuals in the evaluation of health care — not just patients but also those members of the general public who are not currently patients. As a consequence of involving a broader range of people, we need to consider more carefully the type and range of perceptions that we ask people about. Researchers have already established techniques for ascertaining patient satisfaction with services, and there is some information on the views of the general public concerning the availability of services. The next step, I will suggest, is to identify techniques to involve consumers in evaluating the acceptability of treatments.

While existing methodologies are adequate for ascertaining consumer satisfaction with care, they have limitations. These limitations can be overcome by combining methodologies and adopting techniques from related healthcare literature in other areas of medicine.

Ultimately the purpose of seeking infor-

mation about the views of consumers of healthcare, is to use that information to improve existing or to plan new services. I will argue that we cannot simply slot information on the perceptions of consumers into existing decision-making processes. We need to identify mechanisms for dealing with situations in which the evidence from consumers contradicts the evidence from other sources (for example evidence based dentistry, the views of clinicians).

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Who counts as a 'consumer' and what do we want to know from them?

'User' or 'consumer' involvement requires that anybody who is a recipient or potential recipient of care is given the opportunity to

participate in the planning, implementation and evaluation of care. There are four broad groups of people who could count as consumers of dental care:

- Patients
- Carers and relatives of patients
- Ex-patients (both those who have completed treatment and those who have dropped out of treatment)
- Members of the general public who have not experienced treatment

One person may be a member of all these different groups in relation to different aspects of care. For example I might be a patient of general dental services, be a carer of an individual who is receiving care for cleft lip and palate, and have no experience of orthognathic treatment. Different groups of individuals will provide different types of information about the same aspect of care.^{5,6}

It should also be noted that general dental practitioners could be considered as 'consumers' of secondary and tertiary care services. This paper will not address the involvement of this particular client group but many of the same issues apply.

There are three broad aspects of service provision which we can ask consumers about: the structure of the service; the process of the service, and the outcome. The structure of a service relates to the way in which it is organised, its location, the payment system in operation, how patients access the service (walk-in centre versus referral etc.). The process of the service relates to the patient's experience of using the service, and can cover all aspects from receiving an appointment to undergoing treatment etc. The outcome of care can also take many forms, including improvements in aesthetics or function, and the patient's satisfaction with the care they received.

Within these three broad dimensions of care we can also identify seven specific aspects of service quality: availability, appropriateness, acceptability, efficacy, equity, efficiency, humanity.^{7,8} Each of these seven specific aspects could be addressed for the three broad dimensions of structure, process and outcome. However I will argue

¹Senior Lecturer

*Correspondence to Dr Tim Newton, Division of Dental Public Health and Oral Health Services Research, GKT Dental Institute, Floor 18, Guy's Tower, Guy's Hospital, London SE1 9RT.
Email: tim.newton@kcl.ac.uk

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that only some questions can be expected to produce reasonable answers from consumers.

Information on aspects of the structure and process of care may legitimately be requested from patients, and in the case of some patients, their carers or advocates. However, it is important that the views of those who have chosen to discontinue treatment are ascertained as well as those who continue in treatment. For example, drop out rates for treatments have been used as a crude indicator of treatment preference.⁹ Furthermore, a questionnaire or interview to follow-up those who do not complete treatment may yield information which is of value in planning or modifying services.

Measures of patients' evaluation of their dental treatments have been presented in the literature, in particular, patient satisfaction with the process and outcome of care.^{10, 11} The review by Newsome and Wright¹⁰ is a thorough and detailed introduction to the topic.

In terms of the structure of dental services, it has been suggested, both in the dental literature and the general medical literature, that patients do not feel that they have a legitimate role in determining the manner in which limited financial resources are allocated.^{12, 13, 14} In particular, Crossley *et al*¹⁴ suggest that patients are most interested in information on standards, performance and complaints. Patients, and presumably members of the general public, are more concerned with the process and outcome of treatment than the organisational and financial dimensions. It seems reasonable therefore to suggest that patients, carers and the general public will feel unable to make judgements concerning the appropriateness, efficiency and equity of treatments.

Extending this, I propose that the views of the public will mostly address the perceived availability, the acceptability and the humanity of treatments. Such views are an important component of any consideration of the ethics of treatment. The views of patients and carers will focus on the perceived availability of treatments and the efficacy of treatments including perceived outcome and satisfaction with care.

How do we go about ascertaining the views of consumers?

There are three methodological approaches to ascertaining the views of users of their experience of dental services which have been used in the dental literature. These are: questionnaire methods, interview methods and focus group methods. Each has advantages and limitations. I propose that researchers are encouraged to use two or more of these methods concurrently in order to identify the extent to which the findings from each method complement the other.

Questionnaire methods are cheap and effective for surveying large numbers of individuals. The technique can be used to elicit information on a wide range of perspectives. Standardised measures exist for ascertaining patients' levels of satisfaction with their dental care^{15, 16, 17} but most studies have tended to use non-standardised measures.¹⁸ Even well standardised measures of satisfaction may have their problems. Most surveys find that satisfaction data are skewed, that is, the majority of individuals report high levels of satisfaction, however specific items (for example a particular visit) may indicate a more particular dissatisfaction.¹⁹ The problem of identifying specific sources of dissatisfaction when overall the consumers express high satisfaction can be overcome by the use of interviews or focus groups in combination with questionnaires.

Interview methods allow the in-depth exploration of issues and have the advantage over questionnaires of allowing a fuller range of response from the participants. However the analysis of such data can be problematic — the use of strictly defined coding categories may lose the very richness of the data which was the advantage of this method over self completion questionnaires.

Focus group methods are becoming increasingly popular. Similar to interviews, focus groups involve facilitated discussion among a group of 6 to 8 individuals. The information yielded is similar to that of a series of interviews with the addition that the information yielded by the interactions between participants can also be recorded.

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Again analysis is complex.

The three methods outlined above have been used previously to explore a limited range of the views of consumers, mostly satisfaction with care (efficacy) and the availability of care. A thorough and detailed review of published articles reviewing patient satisfaction in the dental literature is provided by Newsome and Wright.¹⁰ These authors suggest that the majority of studies carried out since the 1980s have concentrated on patients' perceptions of service quality, and the extent to which such attributions vary across sociodemographic variables. Approaches to the determination of patient satisfaction have included the use of standardised questionnaires (for example Newton and Breneman²⁰), questionnaires designed by the investigator (for example Fenlon, Sherriff and Walter²¹), questionnaires designed on the basis of qualitative interviews with patients (for example Williams *et al*²²), and interview methods (for example Gurdal *et al*²³).

There is a body of literature in the UK which has addressed the perceptions of members of the general public of the availability of services,^{24, 25} and there has been a small body of work published on perceptions of appropriateness. The data from the Oregon experiment, for example, provide some information on the priorities set by members of the public on dental treatment in comparison with other disease states. It would appear from the contradictory data

produced by the Oregon experiment that the general public finds the setting of the priorities difficult. As mentioned previously the public do not feel they have a role in the allocation of health resources.^{12, 13, 14}

To date there has been no published research in the dental literature which has determined the perceived acceptability and humanity of treatments amongst members of the public and service users. Previous research from the field of mental illness and palliative care has examined the acceptability of treatments from the viewpoint of the general public using vignettes.^{26, 27, 28} In this method participants are presented with case scenarios and asked to judge the acceptability of the treatment in each case. The use of standard vignettes allows the systematic exploration of the impact of outcome and other characteristics on perceived acceptability. Such a methodology provides a model for the appraisal of the acceptability and humanity of dental treatments.

A final consideration is the timing of evaluations. This may influence the perceptions of patients and carers in particular, for example in the short term patients may experience residual iatrogenic symptoms (pain, bleeding, numbness) which will pass with time. The timing of perceptions should strike a balance between being too immediate at the risk of including transitory problems, and the passing of too much time when patients may not remember the treatment experience.²² This will need to be judged according to the particular treatment, and in the light of the expected course of recovery.

How do we use information on the views of consumers in planning services and providing care?

Having ascertained the perceptions of the care recipients of the services they have received, the question arises as to how such information can be included in service planning and clinical decision making. In particular how to use such information when it contradicts other evidence, such as the findings of clinical research, clinical experience or safety.

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delivery are equally effective, with similar side effects, and at similar costs. The treatment of choice would then be that which is most acceptable to patients and families.^{29, 30, 31} Unfortunately, such simple situations are highly improbable. Changing one component of the scenario will change the decision-making process. For example treatments may differ in effectiveness — how much difference in effectiveness would outweigh a clear preference on the part of patients? Should cost considerations outweigh patient preference? For example, previous research with individuals from minority ethnic groups identified that some members would prefer to use secondary dental services rather than primary dental care.³² Does such a preference warrant the additional costs?

At present those involved in planning services are being encouraged to involve consumers in their care, to ascertain their views of treatments and to involve them in planning services. No guidance has been given, however, as to how much weight should be given to this information once it has been gathered and how it should be combined with other information.

A second way in which we may wish to use information on patients' views of treatment

is when making clinical decisions for individuals. While patient involvement in decision-making has generally been viewed as a good thing in itself,³³ clinicians will be aware of the problems that may arise in empowering patients to make treatment decisions. For example, patients may not express a desire for treatment of non-symptomatic caries. These are not only clinical decisions, but ethical ones. A further difficulty arises when we try to generalise from the views of groups of people to a single person. While group preferences may be strong, individuals may hold opposed views (the ecological fallacy). The views of groups of individuals can only act as a guide to clinical decisions in individual cases. In the case of treatment planning for an individual, the clinician must make decisions which balance their own understanding of the clinical situation and the views expressed by the patient. The clinician who gives patients greater involvement in their treatment decisions will need to become a skilled negotiator.

Recommendations

Researchers, clinicians and service planners who intend to carry out evaluations of the views of 'consumers' should

- Clearly state which group of consumers is being addressed. Are these
 - Patients
 - Carers
 - Ex-patients
 - The general public
- Clearly state which aspect or aspects of care are being investigated. Is it the structure, the process or the outcome of care?
- Clearly state which of the following dimensions is being explored:
 - Availability
 - Acceptability
 - Humanity
 - Efficacy
 - Equity
 - Appropriateness
 - Efficiency
- Use a range of methods to ascertain the views of these consumers, including
 - Standardised questionnaires used previously in the literature
 - Qualitative techniques including interviews and focus group discussions

- Develop methods to explore the perceived acceptability and humanity of treatments. Previous research using vignettes provides a model for this.

In using information from consumers in the planning of treatments and services, clinicians should:

- Acknowledge the importance of such information and develop skills to negotiate with patients the extent of their involvement in treatment planning
- Develop guidelines for incorporating such information into planning, and identify methods for resolving discrepancies between this and other information.

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