

Challenges in evaluating primary health care for teenagers

Lionel D. Jacobson MRCGP,¹ Sarah J. Matthews MRCGP², Michael R. Robling BSc(Tech)Hons³, Chris Donovan MRCGP⁴ and the Members of the Research Sub-Committee of the Adolescent Working Party of the Royal College of General Practitioners, London, UK*

¹Research Fellow, University of Wales College of Medicine, Llanedeyrn Health Centre, Cardiff, UK

²Clinical Fellow, University of Wales College of Medicine, Llanedeyrn Health Centre, Cardiff, UK

³Research Fellow, University of Wales College of Medicine, Llanedeyrn Health Centre, Cardiff, UK

⁴Chairman of Adolescent Working Party, Royal College of General Practitioners, London, UK

Correspondence

Dr Lionel D. Jacobson
University of Wales College of Medicine
Llanedeyrn Health Centre
Cardiff CF3 7PN
UK

Keywords: adolescence, individual patient data, meta-analysis, outcomes, randomized controlled trials, systematic review

Accepted for publication:

2 March 1998

Abstract

This paper concerns the evaluation of health care for teenagers and examines the role of primary care and its interaction with the teenage users of this service. It recognizes that the majority of health care for teenagers takes place within general practice. The challenge posed is to identify and put in place suitable evaluation tools. There are government targets to improve the health of teenagers by reducing teenage pregnancy, drug use, smoking rates and suicides. It is an assumption of this paper that improvements in experiences of primary care will lead to improvements in more population-based outcomes of care, although this link needs investigation. The paper shows that there are few measures of generic outcome which are available for use in experiments to assess teenage health care as a baseline now. This has implications for conducting future research projects. Such measures are important and it is a necessary feature of research into teenage health that these measures are devised, tested and validated as a priority.

‘Adolescence and youth form an old topic of conversation but a rather new one for scientific enquiry and sound action based on knowledge’

World Health Organization

Introduction

The *Pocket Oxford Dictionary* is a useful place to start the above enquiry. The definition of a ‘teenager’ is ‘a person from 13 to 19 years of age’, an ‘adolescent’ is ‘a person between childhood and adulthood’ and a ‘youth’ is ‘a young person’. In this paper the terms will be used interchangeably, but the phase is traditionally viewed as a period of turmoil and experimentation. From a health perspective, ado-

lescence can be regarded as a time when smoking, drug use, alcohol use and abuse, emotional distress, and the problems of emerging sexuality (teenage pregnancy, sexually transmitted disease, etc.) start to emerge (Jacobson & Wilkinson 1994).

Teenage health has become a recent area of interest to the health and allied professions in general, and to UK primary care including the academic departments of primary care in particular (RCGP/NASHU 1996). However, there is a paucity of tangible and objective research information available on teenage health in general in the UK (in comparison with the USA, for instance); this is unfortunate considering the health needs of this age group and the requirement for good quality care to be informed

*Research sub-committee members are A. Mellanby (Exeter), C. Donovan (Cardiff), N. Parry-Langdon (Cardiff) and T. Kramer (London).

by useful information rather than conjecture (Macfarlane 1993; Jacobson & Wilkinson 1994; RCGP/NASHU 1996).

It has been government policy to demonstrate improvements in teenage health, although these are usually stated in population terms, for example reducing teenage pregnancy, teenage smoking rates and drug use (Department of Health 1992; Welsh Health Planning Forum 1993). Most of the policy consists of improving health promotion messages, a difficult task to assess and evaluate (Speller *et al.* 1997). Other proposals include altering either the setting or the persons involved (e.g. school nurses and doctors) in health care provision (M. Davis, 'Adolescent Health Care in New Zealand – Current Initiatives: Report Presented to Royal College of General Practitioners Adolescent Working Party', personal communication; Dickson *et al.* 1997) such that health care could be provided in specific clinics in school or elsewhere.

None the less, the majority of health care in the UK is provided by a service which is available to patients of any age, namely the service provided by general practitioners (GPs). GPs are primary care physicians who care for a defined practice population of roughly 1800 patients per GP with ≈ 150 young people aged between 13 and 19 years of age; most GPs work in partnership with other GPs to provide care for a larger population (9110 patients and ≈ 900 young people on average) and have other health professionals (such as nurses and health visitors) to act as a primary care team (Welsh Health Common Services Authority, General Practice Morbidity Database Project, personal communication).

Providing improved care for the teenage population potentially involves the concerted efforts of many health care and other professionals. Clearly, each group should evaluate the services it provides. In primary care, this should include the evaluation of whether the services provided are appropriate, effective and relevant for patients and professionals alike.

The limited evidence which is available supports the hypothesis that teenagers would prefer more patient-centred, approachable, respectful care than is perceived (by them) to exist at present. Most surveys show a level of disquiet of between 20 and 50% of the surveyed teenage population (Bewley *et al.* 1984;

Morris 1985; Macfarlane *et al.* 1987; Epstein *et al.* 1989; Balding 1988; Jacobson *et al.* 1996) which is much higher than levels of disquiet in the adult population at large which usually runs at about 10% (Rees Lewis 1994).

This applies to health services in general and in particular services provided by their GP, where they make further requests for longer time with their GP when they consult (Donovan *et al.* 1997). This latter point is borne out by the research finding that they do have shorter consultations than other demographic groups, although the importance of this is unclear (Jacobson *et al.* 1994).

What emerges from the preceding discussion? It could be that improvements as requested (such as more time and more seriousness) are not feasible in the light of so many conflicting demands placed on the GP and the primary care team. Further, this may be a feature of adolescence that patients are more critical of their health services than others may be, partly because of exaggerated and impractical expectations.

At present we exist in an increasingly 'consumerist' age which values patients' opinions; accordingly one of us (L. D. Jacobson) is involved in a lengthy and detailed descriptive study to tease out the issues of disquiet about primary health care services for young people in the South Wales valleys. Furthermore, the above findings are important because teenage patients who are traditionally viewed as 'healthy' do in fact have many 'unmet needs', and the optimum place to attempt to meet such needs is in a primary care setting (Bewley *et al.* 1984; Epstein *et al.* 1989; Jacobson & Wilkinson 1994).

If improvements in primary teenage health care occurred then the overall health of teenagers may improve. Teenagers may be more prepared to listen to health education messages about their present and future behaviour in individual consultations, and hopefully afford themselves more protection against the effects of 'unhealthy' behaviours (Kari *et al.* 1997; Donovan *et al.* 1997). Therefore, it is theoretically important to assess individual consultations as well as overall care. This paper partially explains why the former may be difficult to achieve in practice.

A review of teenage health has suggested potential improvements in primary care (Jacobson & Wilk-

inson 1994). If these occur, they will need evaluation and consideration, both at individual and at teenage population levels (e.g. practice list, local population or national population). This paper addresses the assessment of improvements in care and the evaluation of quality of care for teenagers in their primary care consultations, whilst it recognizes the inherent difficulties present in such an attempt.

Primary health care measures in general

Structure, process and outcome have classically been presented as the triad of possible measurements in health care (Donabedian 1980). However, the whole area of whether measures of primary care are measures of process (such as blood pressure measurements) or outcome (such as satisfaction or compliance) has become increasingly complex (Pringle 1994). One of the difficulties of assessment is that much of the evaluation of primary care relies less on 'biological' measures and more on 'psycho-social' outcomes; this is at once its strength and its relative weakness.

The Welsh Primary Care Outcomes Group has recently considered this issue (Welsh Primary Care Outcomes Group 1998). The group consisted of doctors with an interest in primary care, including Directors of Public Health and GPs working in the academic area at undergraduate and postgraduate levels. The group concluded that there is an urgent need, both in research and in clinical practice, for measures of the quality of care provided and time-linked generic outcomes within primary care.

It has been apparent for some time that GPs need to evaluate the care they provide to all their patients. However, it is difficult to measure and assess the quality of care provided. Similarly, suitable outcomes of this care may be equally problematic. Linking the two in any interesting and meaningful research investigation becomes necessarily even more complex.

Let us consider the effect of controlling cardiovascular risk factors in adult patients with the aim of reducing cerebrovascular accidents or myocardial infarctions. Improvements in these risk factors will not be accompanied by any obvious reduction in these events at an individual practice level because the relevant practice population is too small. How-

ever, an amalgamated population (e.g. locality or FHSA level, say 75 000 or 300 000 patients, respectively) may see improvements in these events if the risk factors are better controlled (Medical Research Council Working Party 1985).

Many studies in primary care do not take place on such a large scale. Primary care studies are usually smaller partly because it is more difficult to achieve uniformity of intervention or style. In other words, the experimental environment for randomized controlled trials may be more difficult to control due to any number of confounding variables. Further, in the experimental situation in primary care, measures of care for individuals may rely on qualitative methods, whereas measures of generic outcome tend to rely on quantitative measures.

However, the principle of conducting investigations at a single-practice level of say 9000 patients of all ages may make assessment of a given group or single illness within that practice population very difficult. Even if quality and outcome are measurable, interventions are unlikely to result in overtly demonstrable, statistically significant effects when looked at in a single practice. None the less it is appropriate to evaluate care provided by each general practice using outcomes which are relevant to the practice population. The whole principle of evidence as appropriate to primary care has been considered before, including the nature of which evidence GPs may choose to utilize (Jacobson *et al.* 1997).

Evidence does exist demonstrating improvements in the health of adults as a result of using of a more 'patient-centred approach' in such conditions as headache, blood pressure control, diabetic control and breast cancer (Headache Study Group 1986; Orth *et al.* 1987; Greenfield *et al.* 1988; Spiegel *et al.* 1989; Stewart *et al.* 1995). The patient-centred approach involves using a consulting style which relies on eliciting the patient's views, ideas and expectations of care and integrating them into the clinical decision-making process. However, it is difficult to reproduce these findings in the UK for primary care for adult patients with non-specific illnesses, although more patient-centredness is associated with greater levels of satisfaction with the process of care (Kinnersley 1997).

The range of outcome measures which are

appropriate for use in primary care has been extensively described before (Wilkin *et al.* 1992). For instance there are now measures of functional health status (CO-OP charts) which have been validated in the UK for use with adult patients (Kinnersley *et al.* 1994). These measures are a series of six charts where patients can report on physical fitness, mental well-being, daily activities, social activities, change in health and overall health mood and social functioning, and consist of six five-point scales where respondents indicate their health in the past 2 weeks. Likewise, there are many measures of satisfaction with care, including such validated measures as the Consultation Satisfaction Questionnaire and Surgery Satisfaction Questionnaire (Baker 1990, 1991)

These measures can be too time-consuming for extensive, everyday use in routine primary care, although they may be used as audit tools to evaluate quality of care provided by individual general practitioners or partnerships. Therefore, they are necessary for investigations into the effects of differing systems, methods or styles of care. A similar set of tools would be invaluable in evaluating teenage health care.

Primary health care measures and teenagers

It is apparent that the issue of teenage health also needs more extensive investigation. The government has made several areas of health explicit areas for improvement, and it recognizes that the role of the GP is important to meet these targets. However, to evaluate improvements in primary care for adolescents, consultation-specific, generic outcome measures may be as appropriate as assessing such interactions in population terms.

As an example, it is difficult to envisage any intervention in primary care which will result in significant reductions in teenage pregnancy or smoking rates within one practice since the numbers of teenagers 'affected' will be necessarily small. (This situation mirrors the cardiovascular risk factor discussion described above.) Therefore, more appropriate outcome measures which are suitable for consideration at a practice-based level of some 900 teenagers may be more suitable, even though there may still be problems in achieving statistical significance.

None of the measures described above has been extensively tested with teenagers in the UK. Clearly, most have not been designed to be applicable to teenagers. It is appropriate to recognize that teenagers in general share many of the characteristics of other patients, be they older or younger, in that they want a service which is responsive, where they can get appointments at a convenient time and which aids their return to good health.

However, the responses that teenagers may make to questionnaires or interview schedules to discover attitudes, knowledge and responses to health care provision may be different. For instance, teenagers have less experience of the world in general, or may rely on parental or other authority figures to influence their opinions, or as previously stated may feel they need to be critical as a function of their age.

Furthermore, the health problems of adolescents are considered different from those of other age groups, which partly reflects different values within society (for instance, a woman is regarded as more of a concern if she becomes pregnant at 15 years than if she becomes pregnant at 25 years). Further 'unhealthy' behaviours such as smoking or drug use are usually initiated during adolescence (clearly there are isolated reports of young children using solvents as drugs of abuse), whereas older adult patients have now established their pattern of 'unhealthy behaviours'.

It is self-evident that using unvalidated tools on teenage subjects in research trials will create difficulties of interpretation of results. Thus there is an urgent need for these measures to be tested and amended as necessary for use with teenage subjects. In view of the likely differences in the nature of teenage experience, further adaptations to current tools might be necessary to cover differing domains of experience and behaviour.

For instance, in the US a derivation of an adult measure has been developed as a means of detection and early management of health and social problems in teenagers. The researchers used revisions of the CO-OP charts described above (the six scales are five-point Likert scales assessing physical fitness, emotional feelings, school work, social support, family communications and health habits in the past month) and demonstrated that the tools have face validity and acceptability to 291 teenagers in a

school-based series of seminars in New Mexico (Wasson *et al.* 1995).

This tool needs more testing in the US (for instance it has not been subject to further validity and reliability analysis, and has at present been used largely as a screening tool) although it has some promise as a measure of generic outcome in UK GP consultations. Clearly there may also be a cultural and linguistic divide between the US and the UK. It is apparent that more tools need to be developed and tested for use with teenagers.

The need for further measures for teenagers

The above discussion has shown the need to use more suitable measures of care for teenagers. For instance the evidence presented above would suggest that teenage patients would prefer more 'patient-centred care', and if they receive such care may be more amenable to living healthier lifestyles involving less 'risk' to their health. (In this respect they are very similar to their adult relatives.) However, it is still imperative to re-evaluate any 'improved' quality of care as provided to teenagers, to see if it is genuinely better received.

A 22 item questionnaire/tool has been developed to measure a construct called approachability which is intended to measure any changes in reported willingness to re-approach GPs on future occasions for health care. The rationale behind the questionnaire design is to discover aspects of the consultation experience which determine attitudes to attending the GP in future; teenagers in particular have reported finding their GP unapproachable, and the Consultation Approachability Scale was designed to measure aspects of the consultation experience to evaluate care and assess any changes in care provision or style. Preliminary testing has shown that the tool is psychometrically robust and potentially available for use in future projects involving measures of quality of care for all patients, but it was initially developed with teenagers in mind (Hackett & Jacobson 1997).

A further measure which is as yet not developed could assess how teenagers report changes in 'unmet needs'. This might include items such as whether the person was able to raise all issues of concern, whether only one issue was covered, whether health

matters only were discussed, and whether there was an opportunity for health promotion/education.

Clearly, there are outcome measures which need to be developed and considered for issues of validity and reliability and also with their inter-relationship with more 'public health' outcomes of smoking or pregnancy. These generic outcomes may also be used in conjunction with existing knowledge of relatively short consultation times and high levels of dissatisfaction with present services to assess any changes that may occur as a result of differing methods of care.

Future research on teenagers in primary care

The above sections have dealt with measures of generic outcome which in future may allow evaluation of primary care services by their adolescent users. They have not discussed in detail any measures of quality of primary care. This article will not do so in detail, other than to say that many measures of quality of care are present for adult consultations, even though these suffer from problems of validity and inter-rater reliability (Byrne & Long 1976; Pendleton *et al.* 1984; Kinnersley 1997). However, the same potential problems of validity of their use with adolescent patients apply as with the use of outcome measures with groups for which they were not originally devised.

It is worth noting that there still needs to be extensive descriptive research on the teenage and professional perspectives relating to health issues and service provision. Thus the challenge to those who wish to conduct research on teenagers is to continue to look at those areas of disquiet which teenagers may feel and to delineate these such that appropriate interventions may be considered. Further, the means and the method to investigate measures of quality and generic outcome in teenage primary health care must be considered carefully.

The above requirements do, at present, largely preclude the use of a randomized controlled trial research format to investigate 'improvements' in service provision. The main concern of government is not necessarily to see improvements in generic outcomes (such as more empowered adolescents who are more at ease in primary care), but rather to see

improvements in the public health outcomes of teenage pregnancy or teenage smoking rates (Department of Health 1992; Welsh Health Planning Forum 1993).

Conclusion

This paper has discussed how tools which may be used to measure and evaluate the generic outcomes of primary care in UK consultations with teenagers are some way from being available for use. Similarly, measures of process of primary care for teenagers have not been extensively considered. At the present time a paucity of these measures limits our ability to conduct experiments with teenagers to evaluate potential improvements in care.

It is an implicit assumption of this paper that improvements in experiences of primary care will lead to improvements in population outcomes of care, and clearly this link needs investigation. This assumption appears integral to care for teenagers, since the majority of health care provision and health care requirements takes place at the primary care level. In these circumstances care has to be considered on an individual basis to some extent; however, any population can also be considered as a grouping of individual patients.

Since it will be difficult in individual general practices to demonstrate better care producing clear improvements in population measures, we feel it is imperative to consider how improvements in care can be measured which reflect the more individual nature of primary care. This will necessarily involve a set of measures which reflect more 'psychosocial' outcomes of primary care such as measures of approachability, measures of unmet needs, measures of satisfaction or measures of functional health status as noted above.

The development of psychometrically robust tools is a prerequisite for conducting research trials for assessing teenage primary health care. Such development can be funded by NHS Research and Development funding, even though it may not take the form of a randomized controlled trial. We anticipate that the necessary investigations can take place soon such that any improvements in care can be confirmed and allow further evidence to emerge on how to improve teenage health.

Acknowledgements

The authors and contributors would like to thank Dr Paul Kinnersley, Senior Lecturer, University of Wales College of Medicine for his invaluable suggestions on earlier drafts of this paper.

References

- Baker R. (1990) Development of a questionnaire to assess patients' satisfaction with consultations in general practice. *British Journal of General Practice* **40**, 487–490.
- Baker R. (1991) The reliability and criterion validity of a measure of patients' satisfaction with their general practice. *Family Practice* **8**, 171–177.
- Balding J. (1988) *Young people in 1987*. Exeter HEA Schools Health Education Unit, University of Exeter.
- Bewley B., Higgs R. & Jones A. (1984) Adolescent patients in an inner London general practice: their attitudes to illness and health care. *Journal of the Royal College of General Practitioners* **34**, 543–546.
- Byrne P. & Long B. (1976) *Doctors Talking to Patients*. Her Majesty's Stationary Office, London.
- Department of Health (1992) *The Health of the Nation: a Strategy for Health in England*. Her Majesty's Stationary Office, London.
- Dickson R., Fullerton D., Eastwood A., Sheldon T. & Sharp F. (1997) Preventing and reducing the adverse effects of unintended teenage pregnancies. In *Effective Health Care Bulletin*, Vol. 3, No. 1. NHS Centre for Reviews and Dissemination, University of York, York, UK.
- Donabedian A. (1980) *The Definition of Quality and Approaches to its Assessment*. Ann Arbor Health Administration Press, MI.
- Donovan C., Mellanby A., Jacobson L., Taylor B., Tripp J. & Members of the Adolescent Working Party, RCGP (1997) Teenagers' views on the GP consultation and their provision of contraception. *British Journal of General Practice* **47**, 715–718.
- Epstein R., Rice P. & Wallace P. (1989) Teenagers' health concerns: implications for primary health professionals. *Journal of the Royal College of General Practitioners* **39**, 247249.
- Greenfield S., Kaplan S., Ware J., Yano E. & Frank H. (1988) Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine* **3**, 448–457.
- Hackett P. & Jacobson L. (1996) The consultation approachability scale (CAS): an instrument to measure the impact on patients of their general practice situations. *The Wales Office of Research and Development for Health and Social Care* **4**, 6.

- Headache Study Group of the University of Western Ontario. (1986) Predictors of outcome in headache patients presenting to family physicians: A one year prospective study. *Headache* **26**, 285–294.
- Jacobson L., Edwards A., Granier S. & Butler C. (1997) Evidence-based medicine and general practice. *British Journal of General Practice* **47**, 449–452.
- Jacobson L. & Wilkinson C. (1994) A review of teenage health: time for a new direction. *British Journal of General Practice* **44**, 420–424.
- Jacobson L., Wilkinson C. & Owen P. (1994) Is the potential of teenage consultations being missed?: a study of consultation times in primary care. *Family Practice* **11**, 296–299.
- Jacobson L., Wilkinson C., Pill R. & Hackett P. (1996) Communication between teenagers and British General Practitioners: A preliminary study of the teenage perspective. *Ambulatory Child Health* **1**, 291–301.
- Kari J., Donovan C., Li J. & Taylor B. (1997) Adolescents' attitudes to general practice in North London. *British Journal of General Practice* **47**, 109–110.
- Kinnersley P. (1997) *The patient-centredness of consultations and the relationship to outcomes in primary care*. MD thesis, University of Bristol, Bristol, UK.
- Kinnersley P., Peters T. & Stott N. (1994) An instrument for measuring functional health status in primary care: the COOP-WONCA charts. Acceptability, range of scores, construct validity, reliability and sensitivity to change. *British Journal of General Practice* **44**, 545–549.
- Macfarlane A. (1993) Health promotion and children and teenagers (editorial). *British Medical Journal* **306**, 81.
- Macfarlane A., McPherson A., McPherson K. & Ahmed L. (1987) Teenagers and their health. *Archives of Disease of Childhood* **62**, 1125–1129.
- Medical Research Council Working Party (1985) MRC Trial of mild hypertension: principal results. *British Medical Journal* **291**, 97–105.
- Morris E. (1985) *Looking After Yourself – Some Issues from 15 to 19 Year Olds on Health and Illness. Special Report Series 73*. Department of Health, Wellington, New Zealand.
- Orth J., Stiles W., Scherwitz L., Hennrikus D. & Vallbona C. (1987) Patient exposition and provider explanation in routine interviews and hypertensive patients' blood pressure control. *Health Psychology* **6**, 29–42.
- Pendleton D., Schofield T., Tate P. & Havelock P. (1984) *The Consultation: an Approach to Teaching and Learning*. Oxford University Press, Oxford.
- Pringle M. (1994) Outcomes and general practice. In *Outcomes in Clinical Practice* (ed. T. Delamothé), pp. 135–140. British Medical Journal Publishing, London.
- Rees Lewis J. (1994) Patient views on quality in general practice: literature review. *Social Science and Medicine* **39**, 655–670.
- Royal College of General Practitioners National Adolescent & Student Health Unit (RCGP/NASHU) (1996) *The Health of Adolescents in Primary Care*. Royal College of General Practitioners, London.
- Speller V., Learmonth A. & Harrison D. (1997) The search for evidence of effective health promotion. *British Medical Journal* **315**, 361–363.
- Spiegel D., Bloom J. & Yalom I. (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet* **ii**, 888–891.
- Stewart M., Brown J., Weston W., McWhinney I., McWilliam C. & Freeman T. (1995) *Patient-Centred Medicine: Transforming the Clinical Method*. Sage Publications, Thousand Oaks, CA.
- Wasson J., Kairys S., Nelson E., Kalishman N., Baribeau P. & Wasson E. (1995) Adolescent Health and Social Problems: A Method for Detection and Early Management. *Archives of Family Medicine* **4**, 51–56.
- Welsh Health Planning Forum (1993) *Protocol for Investment in Health Gain: Healthy Living*. Welsh Office, Cardiff.
- Welsh Primary Care Outcomes Group (1998) Measuring general practice-based primary care: generic outcomes. *Family Practice*, in press.
- Wilkin D., Hallam L. & Doggett M. (1992) *Measures of Need and Outcome for Primary Health Care*. Oxford University Press, Oxford.