

Original Article

Lay influence on service provision: impact of a Royal College Patient Liaison Group on radiotherapy departments

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Abstract

The Clinical Oncology Patient Liaison Group (COPLG) was established by the Faculty of Clinical Oncology of The Royal College of Radiologists in 1997. One of the early issues to be addressed by the COPLG was the "patient-friendliness" of radiotherapy departments in the United Kingdom. A questionnaire relating to several aspects of patient care was formulated substantially by the lay members of the Group and circulated to all departments. There was a 63% response rate. The results demonstrated considerable variation in departmental practice and they were used as the basis for writing a booklet entitled "Making your Radiotherapy Service more patient-friendly", which was circulated to all departments. This was intended to give practical suggestions on improving services, recommending only what had been shown to be feasible. A year later another questionnaire was circulated, designed to measure the effect of the booklet. There was a 53% response rate. In the great majority of responding departments the booklet had influenced staff and had led to changes in practice and improved care. The service areas most influenced were the provision of facilities for waiting patients, the provision of information about treatment, the maintenance of privacy and dignity and surveying the views of patients.

Keywords

Lay influence; radiotherapy service; patient friendliness

INTRODUCTION

In 1995 the Calman-Hine report, *A Policy Framework for Commissioning Cancer Services*, stated as one of its general principles that the development of cancer services should be patient-centred, and should take account of the views and preferences of patients, their families and carers, as well as those of professionals involved in cancer care.¹ The Department of Health has initiated a widespread programme of reform to modernise the National Health Service, with a commitment to building a

service that is responsive to the needs of patients and the wider public. Key policy documents, including The NHS Cancer Plan, invariably recommend that NHS organizations should involve users (patients, other service users, carers, patients' representatives and the public) across the range of their activity, with the expectation that user involvement will become integral to their work.^{2,3}

In response to the Calman-Hine report the National Cancer Alliance (NCA) undertook a 16 month project gathering the views of cancer patients from four different geographical locations, using a focus group method. The NCA is a charity which was formed in 1994 to bring together cancer patients and healthcare professionals, their

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relatives and friends, to work together to improve cancer care throughout the United Kingdom. The aim of the research was to document the views of cancer patients about the care they had received and to ask the participants to suggest ways in which care could be improved. The findings, published in 1996, confirmed that patients wanted to enhance their quality of life and maximise their chance of survival, but they were concerned also about the way in which treatment is delivered.⁴

Most patients felt their information needs had not been fully met and they wanted information in a language they could understand. This desire for information has recently been confirmed in a large study involving United Kingdom cancer centres, the vast majority of patients wanting a great deal of specific information concerning their illness and treatment.⁵ More specifically, many patients offered radiotherapy have fears, uncertainties and a lack of knowledge about this treatment modality. They can be helped to overcome these through radiographer run information sessions, including tours round the department in small groups, to explain and demystify the equipment and the treatment. In addition there may then be a recognisable face when the patient attends for treatment.⁶

Many patients participating in the NCA project felt strongly that they should be offered emotional support and counselling, or information about how to access it themselves. Many felt that they had not been treated as people by healthcare professionals. Sensitivity, approachability, a willingness to listen and explain, respect and honesty were considered essential attributes in those caring for cancer patients. Another major concern, particularly amongst women patients, was the maintenance of privacy and dignity. The first conclusion of the report was that patients believe that if good practice can be provided in some places it can be provided everywhere. The final conclusion was that when patients are properly consulted and allowed to set their own agenda, they are keen to share their experience and are able to produce sensible, measured and carefully considered recommendations.

“User involvement” is a term which embraces both the involvement of individuals in their own care and collectively, when representatives of patients and other concerned members of the public can

contribute to the formulation of policy and in decision making on planning for the future.² The establishment of medical royal college patient liaison groups has created opportunities for lay people to be involved in debate about widely ranging aspects of healthcare provision at a national level. Most colleges have established patient liaison groups during the past decade. The constitution of these groups varies from college to college but in general they are made up of patients, ex-patients, other lay members with relevant experience, and doctors.

In 1997 the Faculty of Clinical Oncology of The Royal College of Radiologists established the *Clinical Oncology Patient Liaison Group* (COPLG), comprising six lay members, six medical members including 2 ex-officio members – the President of the College and the Dean of the Faculty of Clinical Oncology. The lay members, who serve for three years, were appointed following interviews of applicants recruited through advertisement in the national press. The purpose of the COPLG was to provide a forum for the representation of the views of patients and other lay people and a channel for those views to influence change.

One of the issues addressed by the COPLG shortly after its formation was the “patient-friendliness” of departments of radiotherapy. It was decided to co-opt a therapeutic radiographer to assist with the design of a questionnaire which would be circulated to departments throughout the United Kingdom. The results would be used to formulate realistic advice on improving this aspect of service provision. This could be circulated to all departments with the intention of appraising any effects of that advice in a follow up survey. This process has now been completed and is the subject of this article.

METHODS AND RESULTS

A questionnaire entitled “Is your Radiotherapy Department Patient-Friendly?” was circulated to clinical directors at 57 radiotherapy departments in the United Kingdom in August 1998. This incorporated questions relating to:

- The initial visit of patients and their welcome to the department.

- Appointments.
- Waiting.
- The provision of written information and other forms of communication.
- The maintenance of dignity and privacy.
- The provision of information and explanation concerning the use of permanent skin marks for localization of radiotherapy treatment beams, including discussion of alternatives.
- The provision of clear follow-up arrangements, including advice on personal care and lifestyle and encouragement to maintain general practitioner contact.
- Giving appropriate contact details and information on support groups.
- Assessment of patient satisfaction.

The questionnaire was formulated substantially by the lay members of the COPLG and incorporated suggestions made by individuals who had had recent experience of using radiotherapy services. The design was completed after discussion within the Group and input from clinical directors and superintendent radiographers. Departments were asked if they were already implementing the suggestions for good practice contained within the questionnaire.

There were responses from 36 (63%) departments. The majority of departments had already adopted acceptable policies in most areas, but there was considerable variation and there were obvious areas of sub-optimal practice. For example, in 40% of responding departments there was an expectation that patients would walk partly naked across radiotherapy planning and treatment rooms. Unrestricted access of other members of staff into the room during treatment planning sessions was tolerated in a similar percentage of departments. The most important questions and the responses to them are summarised in Table 1.

The results of the questionnaire survey were used as the basis for writing a 23-page booklet entitled *Making your Radiotherapy Service more patient-friendly*. This was intended to give practical suggestions on improving services and to encourage every department to strive for the high standards already attained in some departments in each aspect of care, through recommending only what had already been shown to be feasible.

The booklet was sent out to clinical directors and superintendent radiographers in the 57 trusts with departments of radiotherapy in the United Kingdom in Spring 1999. In Summer 2000 a second questionnaire, designed to measure the effect of the booklet, was circulated to superintendent radiographers in 64 departments. The circulation list was supplied by the College of Radiographers and included superintendent radiographers based in 4 trusts with two treatment sites and in 3 private hospitals. Responses were received from 34 departments (53%). The main questions and key findings are summarised in Table 2.

The questionnaire asked also for details of changes that had been influenced by the booklet. Most had been specifically recommended in the booklet but some had come about because individual departments had chosen to address certain issues in imaginative ways. Examples of change included:

- Employing a radiotherapy assistant to welcome patients.
- Introducing pre-treatment departmental visits.
- Giving appointments by telephone as well as sending cards.
- Providing more "patient-friendly" written information including a departmental "who's who" and a translation service and picture cards for non-english speaking patients.
- Introducing "recap" sessions on treatment to repeat advice and deal with queries.
- Using screens to divide waiting areas.
- Providing refreshments in the waiting area.
- Providing specially designed gowns for maintenance of dignity for women receiving breast radiotherapy (just exposing the area being treated).
- Incorporating suggestions for maintaining privacy in new departmental design.
- Using the term "permanent skin marks" rather than "tattoos".
- Conducting patient satisfaction surveys.

DISCUSSION

The response rate of 53% from the questionnaire survey on the impact of the booklet was a little disappointing. It is possible that non-responding departments viewed the booklet less favourably

Table 1. Responses to first questionnaire from 36 departments (1998)

Question	Response	
	Yes	No
Do you offer an initial visit to the radiotherapy department before the date of planning?	11(31)	24(69)
Do your patients have an opportunity prior to planning for a discussion with a therapy radiographer?	21(60)	14(40)
Does a member of staff welcome patients in the reception area?	32(91)	3(9)
Are in- and out-patient waiting times monitored?	28(78)	8(22)
Can in-patients wait in privacy?	21(60)	14(40)
Is there a room for patients and partners who may be distressed?	31(89)	4(11)
Are patients who need to undress for their treatment shown to changing cubicles?	23(68)	11(32)
Does your department provide gowns for patients?	28(78)	8(22)
Are patients expected to remove their gown in the planning/treatment room and then walk across the room, partly naked, to the treatment couch?	14(40)	21(60)
Do staff/students have open access to the room where a patient is undergoing simulation or treatment?	13(38)	21(62)
Is informed consent for tattoos obtained prior to the planning session?	25(74)	9(26)
Do you offer an alternative to tattoos?	23(70)	10(30)
Does your department offer same-sex radiographers to patients having radiotherapy to the breast or pelvic area?	11(31)	25(69)
Are patients given appointments for the same time each day?	30(86)	5(14)
Are patients given written literature prior to their radiotherapy planning covering details of the following?		
Planning	30(88)	4(12)
Treatment	31(91)	3(9)
Skin-care	27(87)	4(13)
Tattoos	25(78)	7(22)
Treatment side effects – short term	28(82)	6(18)
Treatment side effects – long term	18(55)	15(45)
Are patients given access to the following?		
Videos	13(42)	18(58)
Tapes	10(34)	19(66)
Facilities to tape consultations	8(26)	23(74)
Media in languages other than English	11(35)	20(65)
Are translation/interpretation facilities available during contact with health care professionals for patients whose first language is not English?	31(94)	2(6)
Do you undertake patient satisfaction surveys on a regular basis?	18(51)	17(49)

Numbers refer to number of departments. Percentages, in brackets, are of the total responding to each question.

and that the responses received overestimate the value of the booklet overall in stimulating change. Moreover, where change was said to have been influenced by the booklet it is likely that in some areas the booklet was merely one of a number of factors that brought this about. There have been massive changes in cancer service organization and philosophy in recent years, involving in particular an increased sensitivity and receptiveness to the needs and wishes of patients. In 1998 half of responding departments were conducting patient satisfaction surveys, but this had

risen to three quarters two years later. Nevertheless, it is clear from the responses to the second survey that the whole process did stimulate change, that changes in practice were facilitated and that patient care improved to a lesser or greater extent in the large majority of responding departments.

Recent NHS guidance⁷ recommends that “clinicians, patients, users, carers and the public can come together to discuss the elements of good quality care and how to deliver it consistently and

Table 2. Responses to second questionnaire from 34 departments (2000)

Which patient friendly procedures were already in place, or were influenced by the booklet?							
<i>Patient-friendly practices</i>	<i>Already in place</i>					<i>Departmental practice influenced by booklet</i>	
Reception area/policy	24(75)					3(21)	
Information about department	27(82)					4(27)	
Appointments policy	31(100)					2(18)	
Waiting facilities	29(88)					10(55)	
Information about treatment	31(97)					7(44)	
Communication and consistency	26(81)					4(29)	
Maintaining dignity and privacy	27(90)					7(44)	
Restricted access to planning	30(91)					4(29)	
Permanent skin marks	24(83)					5(33)	
Follow-up arrangements	32(97)					0(0)	
Surveying the views of patients	23(74)					5(42)	
To what extent did the booklet lead to changes in your department?							
	Not at all	1	2	3	4	5	To a large extent
		7(22)	16(50)	7(22)	1(3)	1(3)	
Was the booklet							
	Not at all	1	2	3	4	5	To a large extent
Relevant?		0(0)	3(8)	7(21)	7(21)	17(50)	
Useful?		0(0)	3(8)	9(26)	7(21)	15(44)	
Clear?		0(0)	2(6)	6(18)	7(21)	18(55)	
Well presented?		1(3)	2(6)	4(12)	9(26)	18(53)	
Was the booklet helpful within your department in the following ways?							
	Not at all	1	2	3	4	5	To a large extent
Changing practice		6(18)	12(36)	6(18)	7(21)	2(6)	
Improving care		4(12)	10(30)	11(33)	6(18)	2(6)	
Influencing management		13(41)	6(19)	5(16)	5(16)	3(9)	
Influencing staff		3(9)	5(16)	13(40)	8(26)	3(9)	
Informing patients		6(23)	7(26)	9(35)	2(8)	2(8)	
Would the provision of a revised document be helpful, taking into account the outcomes of this review?							
Yes	25(78)						
No	3(9)						
No view	4(13)						

Numbers refer to number of departments. Percentages, in brackets, are of the total responding to each question.

appropriately⁷. NHS organizations should include user representation on clinical governance committees, involve users in quality improvement programmes and provide training for both NHS professionals and users about promoting effective patient and public involvement.

There has so far been little evidence on the most appropriate or effective ways of involving users in evaluating and developing services. It is a challenge to try to ensure that the views of patients used in formulating recommendations are representative. It has, for example, been argued that patient questionnaire surveys tend to underestimate levels of dissatisfaction.⁸ In contrast it has been claimed that the application of new rigorous methods to develop and evaluate patient surveys

has meant that they can indeed become valid measures of healthcare quality.⁹

One method of harvesting the experiences and views of patients is the formation of groups who share in focused discussions that are led by a facilitator, recorded and subsequently analysed. Such "focus groups" have been described as being a much more efficient method of gathering data from a cross section of people than individual interviews.⁴ The use of focus groups formed by the random selection of cancer patients has been reported recently to be effective in establishing patient opinion, in making useful recommendations and in integrating user views in the process of service accreditation.⁸ Safeguards are necessary when attempting to involve patients in this way.

While the selection of names obtained from the regional registry was random, the senior partner at each relevant practice was telephoned to ensure that there were no reasons why a selected patient should not be contacted. The patient's consultant also had to agree that it was appropriate for that patient to be invited to take part.

We have demonstrated that the non-randomly selected lay members of a royal college patient liaison group have the potential to facilitate improvement in services throughout the United Kingdom. It is important that recommendations are realistic and are based on what already has been shown to work. The COLPG is now involved in a similar national exercise addressing chemotherapy services.

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