

The '2-week rule' for suspected breast carcinoma: a qualitative study of the views of patients and professionals

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SUMMARY

Background: The '2-week rule' for the referral of patients with potential cancers is an important but controversial development.

Aims: To investigate the 2-week rule for women with breast problems from the perspective of the patients and of healthcare professionals.

Design of study: Qualitative study using semi-structured interviews.

Setting: Patients referred to two breast care units and professionals from primary and secondary care in Teesside and Hartlepool.

Method: Semi-structured interviews with a purposive sample of 12 patients referred under the 2-week rule and 20 professionals.

Results: All women experienced considerable worries in the time leading up to diagnosis. This affected relationships with others, and they used selective telling to help maintain control over their own anxiety and prevent anxiety in others. They were not aware of the 2-week rule as a new initiative, but wanted quick referral to assure them that they did not have cancer. Patients felt they needed more information about breast symptoms and the referral process. Comments about communication with professionals, both good and poor, were frequent in their accounts, which contrasted with the absence of such concerns in the accounts of the professionals. The professionals thought that the 2-week rule was advantageous in reducing anxiety, but thought that disadvantages included longer waits for patients referred outside the rule and increased pressure on hospital services. Cultural changes, including increased patient assertiveness and 'breast awareness', were considered important contextual factors. General practitioners (GPs) were concerned about missing diagnoses in patients statistically unlikely to have carcinomas.

Conclusion: Differences in emphasis were apparent, with patients wanting to be assured that they did not have cancer, specialists concerned both about increased workload and the impact on patients with cancers, and GPs anxious about missing diagnoses. The 2-week rule compromises professional autonomy, which partially accounts for the anger directed against it. There is a need for patients to have more information, and they place great value on good communication. All patient responders experienced significant distress while waiting to be seen.

Keywords: 2-week rule; breast cancer; referral and consultation.

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Introduction

THE '2-week rule' represents a significant organisational change in the referral of patients with suspected cancer. Targets set by the rule include that secondary care specialists should be notified within 24 hours and see patients within 2 weeks from when the general practitioner (GP) decides to refer a patient. The policy was first made explicit in 1997,¹ and introduced for the referral of patients with breast problems in 1999 by updating guidelines already in existence as a new edition.^{2,3}

Women experience considerable anxiety in the period between noting a breast symptom and diagnosis,⁴ though little is known about the nature of that stress and nothing concerning the views of women referred under the 2-week rule. For professionals, the introduction of the 2-week rule has caused considerable controversy, with complaints of increasing workload for secondary care specialists.⁵ There are also claims that it has failed to achieve the purposes it was designed to meet,⁶ although different aims and agendas are apparent in the policy.⁷

The aims of this study were to compare the views of patients and professionals concerning the process of referral under the 2-week rule for breast problems. We aimed to study patients' personal experiences of the process, including the effect on themselves and their families. We also aimed to investigate professionals' views about the advantages and disadvantages of the 2-week rule for patients with breast problems.

Method

Qualitative methods were used, with semi-structured interviews conducted with patients referred under the 2-week rule, and with professionals from a number of disciplines.

Recruitment

For practical reasons, including time constraints, the number of patients interviewed was determined at the outset. New patients attending clinics at two breast specialist centres were given leaflets explaining the study that incorporated a reply slip if they wished to participate. They were invited to return the reply slip, either at the time of the clinic or later if they wished to consider it further. Patients referred under the 2-week rule were selected from the replies for further consideration. All men, and women diagnosed with breast cancer previously were excluded. From the group of potential participants, six were chosen at random from each centre. The ages of the women ranged from 36 to 70 years; four were professional women, three

HOW THIS FITS IN*What do we know?*

The '2-week rule' for urgent referral of breast symptoms is an important but controversial development.

What does this paper add?

Patients wanted quick referral to assure them that they did not have cancer, specialists wanted quick referral for patients with cancer. Patients placed great emphasis on the need for good communication and information, which was absent from the accounts of professionals.



were retired, two were housewives, and three worked in an office, shop or secretarial capacity. Breast cancer was diagnosed in two of the patients.

We used a pragmatic approach for recruitment of the professionals, deliberately choosing from a variety of disciplines to provide as wide a range of views as possible. The professionals from secondary care were all involved with the breast services from three hospitals. A variety of GPs from the same area covered by the hospitals were selected, some because of special interests such as work in the Cancer Care Alliance. We aimed to recruit four GPs initially, but following initial analysis it was apparent that further GPs were needed. Letters of introduction and explanation about the study were sent to all of the professionals asked to take part.

All (nine) of the GPs worked in urban group practices and two were female. Of 11 secondary care specialists, six were female. The professionals varied in experience from a recently appointed GP principal and consultant surgeon, to surgeons of considerable experience of treating patients with breast cancer and of organising breast care services. All participants who agreed to take part were contacted by telephone and a choice of venue was offered. Details of the participants are given in Tables 1 and 2.

The interviews

A breast care nurse interviewed the patients (all except two were conducted in patients' homes) and a GP interviewed the professionals (all except one at their work places). The interview schedule for the patients included their experience of being referred, the effect on themselves and their families, the speed of the referral, and their opinions on care received from presentation to reaching the clinic. The schedule for the professionals included their views about the 2-week rule; why the rule had been instituted, what the rule requires professionals to do, and positive and negative aspects of the policy. The interviews lasted between 30 and 90 minutes, were audiotaped and transcribed verbatim. Each interviewer also wrote field notes.

Analysis

Data were analysed principally by the individual researcher conducting the interview. Both researchers read the transcripts, either of the patients or of the professionals, several times for immersion in the data, and both used a form of constant comparative approach in analysis.⁸

Table 1. The patients.

	Centre one	Centre two
Number of invitations given out	60	Data unavailable
Number of replies returned by 2-week rule patients	16	Data unavailable
Number interviewed	6	6

Table 2. The professionals.

Speciality	Number interviewed (number invited)
GPs	9 (13)
Consultant surgeons	5 (5)
Breast care specialist nurses	3 (3)
Consultant radiologists	1 (2)
Radiographers	1 (1)
Manager	1 (1)
Total	20 (25)

The interviewer of the patients used Burnard's model,⁹ starting with broad headings, then identifying more detailed codes before deciding on higher order headings. The headings and codes from this analysis of the patient interviews were combined into a list of eight themes. Each patient interview transcript was colour coded, and the codes cut and pasted under themes in preparation for writing up.

The interviewer of the professionals identified detailed codes from the transcripts. After several interviews had been coded, a 'scatter diagram'¹⁰ was used to decide on 'pattern codes' — themes bringing together a number of the codes. Further coding from subsequent interviews with other professionals resulted in a modification of the themes.

Independent researchers analysed all of the interviews with the patients and three of the interviews with professionals, and the results of the analyses were compared and discussed among the researchers.

Results

A total of 11 themes were identified from the interviews with patients and professionals, six of which were solely from patients' interviews, three solely from professionals' interviews and two common to both groups. Some of the themes, such as reduction of anxiety, were based on descriptive codes derived directly from responses to interview questions; others, such as loss of professional autonomy, were more interpretive and based on data from a number of questions. The sections that follow incorporate a number of the initial themes.

Patients' fears, relationships with others, and selective telling

Personal fears, which women experienced throughout the referral process, came across very strongly in the interviews. Fears included imagining not only cancer, but also death and mutilating surgery:

'I don't know if cosmetically the final result would be acceptable for me.'

None of the women were certain that they did not have cancer, and all expressed fear while waiting to find out. The following women expressed the anxiety experienced:

'If I started thinking about it, I'd tell myself to stop, otherwise I'd have all these morbid thoughts.'

'During the hour I sat and waited, I began to realise that it might be a great deal more serious than I thought.'

Personal fears about the symptom and the consequent wait affected relationships with others. Often the needs of others were placed first:

'I paid loads of bills so my husband wouldn't have to do it. I bought loads of food.'

Some found it difficult to take on other peoples' grief as well as their own, and consequently made light of the situation or did not tell them:

'I didn't take my husband, I couldn't handle his emotions as well as my own.'

They were selective in whom they told for other reasons. Some were reluctant to tell male work colleagues:

'I was reluctant to tell anyone at work, mainly because it's predominately male partners I would have to speak to.'

And some would avoid telling others to protect them, particularly parents:

'I never told my Mam, she's in her seventies and I couldn't burden her.'

Reduction of anxiety

None of the women could explain the 2-week rule or define it as a new initiative, although all were aware of the risk of cancer, that it should be taken seriously and dealt with early. What women wanted from a quick referral was to be assured that they did not have cancer:

'I was aware that there has been a lot of publicity, a lot of Government bumph about getting people in within a short space of time in order to cut down on worry.'

An urgent referral for the women was appreciated as a speedy reassurance that they did not have cancer:

'They get you in quick to let you know everything's alright, and that's all you want really.'

Most professionals mentioned that women with carcinomas referred under the 2-week rule would be assured that whatever could be done, would be done quickly, although they believed that no improved survival rates would result. The professionals also believed that women referred within

2 weeks and without carcinomas would be quickly reassured, an important consideration for many of the GPs. This GP gives an example of a 'good' referral:

'I mean it would be that you've been referred quickly for a suspected cancer and it was found not to be, so I mean that is good practice as well because, ya know, you've sorted out the patient's problem and you've removed a cause of immediate anxiety.'

Disadvantages of the 2-week rule

All professionals saw potential or actual disadvantages that were more strongly stated than the advantages (particularly by those working in secondary care).

Some professionals felt the policy had caused problems for patients referred outside the 2-week category. Many such patients inevitably would have cancers and were waiting longer, as explained by a surgeon:

'The clinics are at least 6 weeks backlog but only 20% of cancers get picked up on the 2-week rule so that 80% of cancers are in the 6 week backlog and it's getting bigger.'

Other professionals felt that, although currently patients referred outside the 2-week category were being seen reasonably promptly, problems would result if waiting times increased.

The most strongly held criticism was that the 2-week rule had put increased pressure onto the service. This, at best, had necessitated a reorganisation of clinics, but clinics were also longer and busier, and staff were more stressed.

The patients and GPs

Communication skills were emphasised as being of crucial importance by the patients throughout the referral process. Both positive and negative comments were made. Communication was classified as 'good' or 'bad' depending on the amount and nature of information provided as well as how it was given. Some appreciated knowing the GPs' provisional diagnosis, but others felt too much information was given, particularly for one woman who was found to have a benign cyst:

'She was quite blunt with me and said "you obviously know you've got a lump, I think you should both prepare yourselves for the worst". She said I would be more than 99% sure it could be cancerous.'

Women recognised that GPs might not be able to tell them what was wrong at the consultation, and didn't appear to mind as long as they felt something was going to be done. None of the women felt that their symptoms were trivial (even after cancer had been excluded) and they felt their concerns should be taken seriously.

In contrast, the professionals did not discuss difficulties in communication, but emphasised other problems. The GPs recognised the difficulty in always making a correct diagnosis. Any lump might potentially be malignant — indeed there might be a malignancy without any definite lump — and there were problems with 'borderline' cases. Most GPs

also had personal experience of young women with breast cancer. Therefore, in assessing a woman with a lump, youth was not necessarily reassuring. The GPs varied in the extent to which they could accept calmly the uncertainty about a diagnosis, but agreed that any increased waiting time for non 2-week rule patients might pose a problem. One GP stated:

'You sometimes get surprises with breast lumps and I think there are occasions when I tick the 2-week box where I'm not deep down really thinking they've got cancer but I'm just a little bit reluctant in case they go to the back of a long queue.'

Secondary care professionals were careful about placing too much blame on GPs, acknowledging the difficulty in making a 'correct' diagnosis on clinical evidence alone.

Secondary care professionals felt GPs were under increasing pressure from patients. General changes in attitudes included patients who were better informed, more aware of 'rights', and had greater expectations. Specific cultural changes towards breast cancer included an increase in 'breast awareness' and increased media attention, often portraying breast cancer emotively. A few thought that the increase in breast awareness was beneficial, in that women would present earlier with breast symptoms, but many saw it less positively and as a source of increased pressure for all the professionals involved.

Although they acknowledged that GPs worked under these (understandable) difficulties, many secondary care professionals thought that GPs referred inappropriately on occasion, and claimed that the threshold was too low and that they were not following the 'guidelines'. This was sometimes attributed to ignorance, but also to GPs occasionally misusing the system deliberately as an easy method of dealing with a problem:

'Patients are now prepared to challenge their GPs and obviously if you've got a 10 minute consultation if ya lucky I can assume that the GP is under pressure and the easiest thing is to tick a few boxes on our referral form and stick it in the e-mail or stick it in the fax machine or get somebody else to do it.' (Secondary care professional.)

Loss of professional autonomy

The professionals' ill feelings against the 2-week rule ranged from mild irritation through to sarcasm and anger. Ideas about loss of control were expressed by many of the professionals. Those who were most angry expressed clearly their feelings of loss of autonomy. Some GPs felt constrained by the necessity to include a patient in a particular category. Secondary care professionals felt constrained by the requirement to accept the GP's classification. The following two professionals were particularly angry:

'The introduction of the 2-week rule now has totally de-professionalised me as a person, I feel, and it's caused mayhem with the clinic. I can no longer prioritise my clinic.' (Surgeon.)

'They come up with the bright idea that cancer cases should not be waiting for longer than 2 weeks ... It hasn't been a proper consultation with the medical profession.' (GP)

The women, who were unaware of the 2-week rule as an initiative, also failed to feel in control, but for other reasons. Some women felt unable to voice dissatisfaction with their care. Many felt they needed more information about breast disease including which symptoms to be concerned about. Some would also have appreciated more information about what would happen at the breast clinic:

'I wasn't sure what would happen, I don't think I thought it would be all done that day.'

Discussion

Summary of main findings

The anguish experienced by women waiting for a diagnosis came across strongly in the study. The fears of cancer, mutilation and death affected relationships with others. Women selectively told others, sometimes to protect themselves from too much grief and sometimes to protect the other person. They emphasised the importance of good communication with professionals and needed more information. Women wanted a speedy referral to assure them that they did not have cancer.

Professionals expressed the difficulty of making a diagnosis of cancer on clinical features only. They were concerned that the 2-week rule would cause clinic disruption and adversely effect provision of timely care for patients with cancer. The 2-week rule compromised professional autonomy.

Strengths and limitations

This study has enabled important comparisons to be made between the views of different professional groups and patients about an important policy. A limitation of the study was that we did not interview patients referred to breast services outside the 2-week rule. These patients may have different fears and views to the patients referred under the 2-week rule, although none of the patients interviewed were specifically aware of the 2-week rule as a new initiative. The professional participants were drawn from only three hospitals and the patients from only two specialist units. The emphasis in this paper has been on reporting differences between groups and some details of differences between individuals within the same group may have been understated.

Comparison with existing literature

Worry and shock at diagnosis are commonly experienced by patients with breast cancer,¹¹ and placing the needs of others before their own may be a reason for delayed reporting.¹² Relatively little is known about worries for patients without cancer, although fears about cancer are known to be a persisting problem for women recalled after screening but found not to have breast cancer.¹³

In some ways, annoyance with the 2-week rule is a continuation of previous concerns. Increasing workload, GPs' failure to keep to guidelines, increased media attention,

increased awareness of breast problems, and increased pressure from patients have all been expressed before.¹⁴⁻¹⁶ The 2-week rule represents a further, formal, restriction in professional autonomy, felt to a variable extent by the professionals interviewed. In particular, some professionals felt that it prevented them from assessing priority according to their own assessment of an individual's need. The extent of anger expressed may be explained by the extent to which autonomy is felt compromised, the extent to which the compromised autonomy is felt reasonable, and the extent to which the professional feels overwhelmed by work demands and lack of resources. One of the key concerns for professionals is the effect of delays on mortality outcomes, and despite conflicting evidence,^{17,18} it would seem unlikely that 2 weeks would make an appreciable difference.¹⁹ Although there was no evidence in our study that this showed itself directly in adverse behaviour to these groups, annoyance with the policy for secondary care professionals is likely to show itself in annoyance against patients and GPs.

The importance of good communication between professionals for patients with breast problems has been described before;²⁰ this study shows the need for a deeper understanding between the different groups. This might include sharing the uncertainty of making a clinical diagnosis with the patient.

Implications for practice and future research

The study indicates that there is a need for more information for patients, including women who do not necessarily have carcinomas. Patients with cancer need information,²¹ although there is a variation in need between patients, and for the same patient at different stages of the illness.²²⁻²⁴ Resources, helplines, counselling services, and information leaflets are often targeted at women diagnosed with carcinomas, but should equally be available for those with breast symptoms unrelated to breast carcinoma. Women need more information about breast symptoms and a more definite view of the likelihood that they have breast cancer,⁵ and a more realistic and optimistic view of treatment for breast cancer.

There are two contrasts that we wish to emphasise between the accounts of patients and professionals. The first concerns the purpose of quick referral. Patients want early referral to assure them that they do not have cancer, specialists want early referral for patients with cancer, and GPs want both. The distress felt by all waiting patients was very evident. Specialists view early referral as a means to diagnose cancer and to provide excellent timely care, principally for patients with cancer, and are therefore mainly concerned about how the policy has an impact on patients with cancer. GPs wish to ensure patients' anxieties are addressed and that no unnecessary risks are taken. Problems with conflicting agendas will be exacerbated if waiting times for patients referred outside the 2-week rule become significantly extended.

The second contrast concerns the importance that women placed on good or poor communication with professionals and the absence of such comments in the professional accounts. How communication might be

improved goes beyond our study, yet this difference in emphasis indicates that further work in this area, both research and educational, needs to be carried out.

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