

Research paper

Patient choice: an exploration of primary care dermatology patients' values and expectations of care

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ABSTRACT

Background Skin complaints are an important cause of ill-health accounting for a large number of general practitioner (GP) consultations and referrals to secondary care. Organisational developments in the UK have led to GPs with a special interest (GPSI) in dermatology offering outpatient services in a primary care setting; however, an in-depth exploration of the values dermatology patients attach to aspects of care or the acceptability of variations in secondary care service delivery has not been reported.

Aim To identify and explore the aspects of care dermatology patients deemed important in making choices about service use.

Design A qualitative study carried out alongside a randomised controlled trial to compare effectiveness of a GPSI dermatology service with standard consultant-led dermatology outpatient care.

Setting United Kingdom.

Method Semi-structured interviews with primary care patients referred for routine dermatology outpatient appointments.

Results Participants referred for routine outpatients appointments had skin conditions which

ranged in severity and impact on their quality of life. Those with minor skin complaints expected their GP to be able to provide more treatments at their local surgery. Some participants who had experienced unsuccessful treatment by their GP reported difficulties in obtaining a specialist referral. Variation in perception and relative importance of the constituents of specialist care was highlighted. Primary care-based specialist services are not always accessible to those living outside the immediate vicinity.

Conclusion GPs should be aware of the impaired quality of life experienced by some patients with chronic skin complaints. GPSI services were acceptable to the majority. However, there is likely to be a group of patients with longstanding, though clinically non-urgent, conditions for whom the service will not be acceptable.

Keywords: dermatology, GPs with a special interest (GPSI), patient preferences, qualitative research

How this fits in with quality in primary care

What do we know?

- Skin complaints are an important cause of ill-health, accounting for up to one-fifth of all general practice consultations in the UK and large numbers of referrals to secondary care.
- People with skin complaints report an impaired quality of life, and their psychological health can be affected.
- Current health services policy encourages development of secondary services being offered in a primary care setting, developing specialist expertise among GP and other primary care staff, increasing choice for patients.
- Dermatology services have been identified as an area where there is potential to reduce waiting lists and improve services for patients

What does this paper add?

- People with minor skin complaints expected their GP to be able to provide more treatments at their local surgery.
- Participants who had experienced unsuccessful treatment over time by their GP reported difficulties in obtaining a specialist referral and may constitute a patient group for whom GP with special interest (GPSI) services are unacceptable.
- Variation in perception of and relative importance of attributes of 'specialist' care was highlighted.
- GPs may be able to influence patient demand for services by their choice of language relating to specialist care and reassurance of patients presenting with non-urgent skin lesions.

Introduction

Skin complaints are an important cause of ill-health, accounting for up to one-fifth of all general practice consultations in the UK.¹ Furthermore with increasing numbers of older people, for whom skin complaints are an important cause of morbidity, the need for dermatology services is likely to grow.² People with skin complaints report an impaired quality of life and their psychological health can be affected.^{3,4} Although, in the UK, the majority of patients are cared for by general practitioners (GPs) who manage common skin diseases such as viral warts, eczema and benign tumours in the community,⁵ there are a large number of referrals to secondary care (over 600 000 in 2001 to 2002), mostly managed on an outpatient basis.¹

Current government policy encourages the development of some specialist services to be offered in a community setting, with the aim of making best use of resources, developing specialist expertise among GPs and other primary care staff, and increasing choice for patients.^{6,7} Dermatology services have been identified as an area where there is potential to reduce waiting lists and improve services for patients.^{1,8} Guidelines have been developed for the training and support of GPs with a special interest (GPSI) in dermatology to offer an outpatients service in a primary care setting.⁹ It was proposed that by 2006 10% of all outpatients appointments should take place in the community.¹⁰ A recent trial found there were no differences in clinical health outcomes between dermatology patients cared for by a GPSI compared to those who received standard consultant-led outpatients care.¹¹ However, to date little is known about UK dermatology patient attitudes to variations in secondary care service delivery or the values they attach to aspects of the care they receive.

This paper reports the findings of a qualitative study carried out as part of a randomised controlled trial (RCT) comparing costs and outcomes of care for patients receiving treatment for skin complaints at either a hospital consultant-led outpatient clinic or a primary care dermatology service (PCDS).¹¹ The

hospital is located in a city centre and serves both the immediate urban population and people living in semi-rural communities up to 20 miles away. The PCDS is based in a health centre on a suburban estate run by two GPs with a special interest in dermatology (giving four sessions per week) and a specialist nurse. Both GPSIs have a postgraduate diploma in practical dermatology, had been on the British Society of Dermatological skin surgery course and had been clinical assistants in dermatology for two years. They received clinical support for two sessions per month from a consultant dermatologist. They provide non-urgent general dermatology services and some skin surgery. The qualitative study aimed first, to identify and explore the aspects of care people with skin conditions valued in making choices about service use; and second, to develop the attributes and levels for a discrete choice experiment (DCE) questionnaire to assess quantitatively dermatology patients' preferences for care, reported separately.¹²

Methods

The purpose of this study was to seek and explore the experiences and understandings attached by people with skin complaints to the health services available to them, and for this reason qualitative methodology is appropriate.¹³ Following the end of recruitment to the main trial, similar patients, that is, new referrals over the age of 16 years requiring routine outpatients appointments, were purposively selected from GP referral letters for interview, sampling for maximum variation in age, sex, presenting conditions and proximity to the service. Information about the study and an invitation to be interviewed were sent to patients with their booking letter. The researcher then contacted those patients who submitted their personal details by telephone or letter (SH) to arrange an interview at their convenience. Since patients' expectations might have been coloured by previous experience of dermatology services, some interviews took

place before and some after treatment to obtain as diverse views and experiences as possible. Those participants who had received care were interviewed within two weeks of their appointment. Patients gave written consent for interviews, which were taped and transcribed.

Semi-structured interviews were conducted, although participants were encouraged to explore their own priorities for care in the course of the interview (see Appendix 1). Topics for inclusion were identified by literature review and examination of comments on the consent forms about the reasons patients gave for declining to participate in the RCT. Issues relating to the convenience of the PCDS location and preference for consultant-led care were the most frequently cited reasons for not participating in the main trial. The interview schedule also included details of patients' history and experience of obtaining care for their skin complaint, waiting time for the outpatients' appointment and preferences for specialist care. Interviews were held from September 2003 to June 2004.

Analysis

Interviews were transcribed and coded using ATLAS-ti, a software package designed to assist in organisation of data for qualitative studies.¹⁴ An iterative approach to analysis was used, with initial coding and analysis proceeding during the course of interviewing and informing the sampling strategy. Reliability of coding was assessed by the first interviews being read and coded by SH, then by another researcher (JC) and compared. Initial coding was then organised into categories that illustrated the interplay of factors emerging from the interviews. Disconfirming accounts were actively sought in order to strengthen the analysis.¹⁵ In order to explore any possible relationship between the nature and impact on quality of life of the skin complaint and participants' views on the acceptability of the PCDS, experiences of severity of the presenting skin complaint were compared. Interviews proceeded until no new factors emerged.

Results

Twenty interviews were carried out. All the interviews except one took place in the patients' homes and lasted from half an hour to an hour and a half. In two cases the participant's spouse contributed to the interview.

Participants

Nine participants lived either in or around the main urban centre where the hospital dermatology outpatients department was situated. The remainder lived between nine and 20 miles away. At the time of their interviews 14 had already attended their appointment, while one had taken the option of private treatment due to the wait anticipated by her GP. Five patients were awaiting their first appointment. Table 1 shows where patients received care and whether they had received care at the time of the research interview.

Participants presented with a variety of skin complaints, ranging in severity from painless but undiagnosed skin lesions that may have significance for long-term health to chronic conditions such as psoriasis and eczema with significant effects on the individuals' quality of life. A minority of patients referred for non-urgent outpatient appointments expressed considerable and longstanding distress, anxiety or pain arising from their skin complaint.

Acceptability of a primary care-based specialist service was influenced by four interrelated themes: participants' perception of their need for diagnosis or treatment (urgency), which influenced willingness to wait for a specialist appointment; previous experience of primary care services; perceptions of the meaning of 'specialist' expertise; and factors relating to the convenience of the respective services. Variation as to the relative importance of each theme existed according to whether the participant perceived their skin problem as urgent or painful or not.

Need for diagnosis or treatment

Perceptions of need for access to specialist care appeared to be markedly different between participants. Some participants expressed surprise that what seemed to them to be a relatively minor problem could not be managed by their own GP.

'Presumably it is on my notes what happened last time and what the treatment was. It did seem, why am I having to wait this length of time to go and see someone, when I know what the treatment will be (and indeed it was)! So why have I got to see a real specialist? Couldn't my doctor have done it?' (3, male, Bowen's Disease)

Most participants seemed aware of the potential significance of skin lesions, and this instigated a sense of urgency for diagnosis and treatment, although the reassurance of a GP seemed to allay fear and make more acceptable a 4–8-week wait to see a specialist.

'I suppose I felt reassured that because I thought ... if she'd looked at it and thought "this is definitely a melanoma", then I would be seen a lot quicker, I'm sure. In a way, I was reassured and I didn't mind the wait in that sense, although I wanted it healed up really.' (20, female, solar keratosis)

Table 1 Characteristics of participants

Participant	Age	Sex	Diagnosis	Location of care	Own transport	Comment
1	83	F	Urticaria angio-oedema	PCDS	N	
2	20	M	Undiagnosed	Hospital ^a	N	Offered PCDS and refused
3	73	M	Bowen's disease	PCDS	Y	
4	47	M	Psoriasis	Hospital	Y	Offered PCDS and refused
5	72	M	Infected nail	PCDS	Y	
6	33	F	Undiagnosed mole	PCDS ^a	Y	
7	32	F	Alopecia	Private	Y	Offered PCDS too late
8	75	M	Solar keratoses	PCDS	Y	
9	45	M	Wart on eyelid	PCDS	Y	
10	43	F	Eczema	Hospital ^a	Y	
11	51	M	Psoriasis	Hospital	Y	
12	83	F	Bowen's disease	PCDS	Y	
13	31	F	Contact dermatitis	PCDS ^a	Y	
14	73	F	Solar keratoses	PCDS	Y	
15	83	M	Undiagnosed	PCDS ^a	Y	
16	56	M	Undiagnosed	Hospital	Y	
17	66	M	Undiagnosed	Hospital	Y	
18	53	F	Psoriasis	Hospital	Y	Would have paid for private treatment if appointment not offered almost immediately
19	47	F	Urticaria	Hospital	Y	
20	47	F	Solar keratosis	Hospital	Y	

^a Not yet attended their appointment.

Those participants who considered their complaint relatively minor expressed no reservations about attending a GPSI for diagnosis and treatment, accepting that a doctor with appropriate expertise in dermatology would offer a suitable service. However, it was clear a GPSI would not be acceptable if the patient perceived that they had a potentially life-threatening condition. For the majority of participants a shorter waiting time for their appointment combined with an appropriate level of expertise for treatment of their condition made

the GPSI an acceptable service, especially if they had already been waiting for referral or an appointment for some time.

Experience of primary care services

Participants reported considerable variation in their GP's attitude to their skin problem. Those requiring a diagnosis for a visible, undiagnosed skin lesion did not report any problems with obtaining a referral for an

outpatient appointment. However, this was not the experience of participants with longstanding skin conditions, who reported ineffective treatments from their GP, and a lack of understanding as to how their lives were adversely affected by their skin condition (pain or itching, time-consuming application of creams, clothing ruined, embarrassment, or feeling unable to expose arms and legs, sleeplessness and depression, some were also being faced with a need to consider a different career). Lack of satisfaction with skin consultations in primary care could have implications for the acceptability of an appointment with a GPSI. It was a common experience for participants with chronic skin complaints to consult their GPs over a number of months, themselves eventually instigating the referral with varying degrees of unease. Difficulty in obtaining a referral to specialist care was commented on, and in some cases referrals were eventually made, not by their usual GP, but by another GP in the same practice, or a locum.

'I said "I would have liked you to do that [refer for a consultant opinion] a long time ago", you know. So she said she would get on with that. And then I saw her two months after that and I said "you realise that it's almost two years now".' (1, female, urticaria angio-oedema)

'So maybe 6 months ago I went to the GP and I asked, well I said, "look nothing is happening, how about referring me?". And I understand there was some reluctance to do that because the practice has to pay for a referral ... I particularly liked him, I think he is the most sympathetic in the practice and I said "it is me again, still no joy" and he was about to offer more of the same and I said "well I wondered about taking this a step further, and maybe going to see a dermatologist". I mean it is not his face fell, but he – put it another way – he might have suggested it himself, and maybe he was about to – and I got in there first. But I don't think so. I think he was all for writing me out another prescription as opposed to "OK, I can't do anything – I know someone who can".' (4, male, psoriasis)

'Well, it takes a long time to be referred and often badgering, and I hate badgering the GP. And I don't think one should actually have to badger a GP for something because it makes me feel, I don't know, a bit grubby having to badger them.' (10, female, eczema)

The experience of having repeated, failed treatments in the context of consultations with their GP may have a bearing on patients' perceptions of the desirability of an alternative dermatology service run by a GPSI. In fact two participants refused the offer of the PCDS despite being offered an earlier appointment, because they wanted to see a consultant, someone with expertise beyond that they perceived to be possessed by a GPSI, both having been unsuccessfully treated by their own GP for their complaint (2 and 4).

Specialist expertise

There was considerable variation in understanding of the term 'specialist'. Specialist care was equated with an increased expertise in a particular field, and not necessarily linked to an explicit title or grade of staff. Those who perceived their skin complaint to be minor were content to be seen by either a doctor or a nurse if they were skilled in that particular area,

'Well, I mean if you've got, you can get sort of nurses that specialise in certain ... I wouldn't expect it to be somebody who's, you know, qualified over and above a GP or a doctor, um, as long as they specialised in the field ...' (7, female, alopecia)

Participants rarely made a distinction about the relative expertise of hospital doctors. Hospital doctors were perceived to offer high-quality care, the hope of diagnosis and effective treatment, awareness of research and new therapies, confidence and reassurance. Terms such as 'top man' (3 and 4), and 'boss' (19) were used to describe consultant dermatologists in hospital outpatient departments. Seeing the consultant was particularly important for participants who had experienced repeated and unsuccessful treatments with their own GP and lacked confidence that a GPSI would have sufficient skill to manage conditions similar to their own.

'I think in this case, because I've seen a GP who'd not [pause] unlocked the riddle, not helped me, so I thought "well". And this consultant was described by the GP, you know he's your man. So he was described as the man to see, devoted his life, as opposed to someone who has maybe done some training.' (4, male, psoriasis)

'I would want to be seen by someone who was a specialist. Who had extensive experience and, and, and would know about the sort of conditions. So that's the whole point and I see the GP as a filtering service ... If I'm going to be referred then I'd want to be sure it's to someone who was a specialist and not someone who knew a little bit more than the next doctor.' (16, male, undiagnosed)

To identify and explore the constituents of specialist care particularly valued by participants, their experiences of consultant appointments were sought. The quality of the interaction between doctor and patient in these consultations did not seem to be valued in this context. Even if a cursory examination or limited communication or interaction were perceived, these apparent shortcomings were justified by the participant's confidence that the depth of the expert's knowledge and experience negated the need for a thorough examination or interview for effective diagnosis and treatment.

'I think, I mean the GP had a better look than the fellow I was referred to, but then he spends his whole time doing it – so I didn't feel, hmm, that was a bit glib, because I accept

he knows what he is looking at from a distance of 6 feet. He should know what he is looking at.’ (4, male, psoriasis)

‘I mean I took a photograph when I had a very bad attack and I took the camera with me and I said to her, the woman, would you – shall I show you this photograph and I thought well actually no, suddenly it melted away – it’s a silly idea because I thought she knows exactly what I’m talking about because she’s seen hundreds of people probably with it and I didn’t feel offended but some people might have, they’ve gone to the trouble of taking the photograph and remembering to bring it with them and actually probably I should have ... She should probably have looked at it just to humour me.’ (19, female, urticaria)

Convenience

Other aspects of care valued by participants related to ease of access and the perceived convenience of location (journey length, time, ease of public transport links or access to secure parking), time saving, cost, other local facilities and flexibility of appointments systems. While for the most part participants thought the provision of services locally was a good idea in principle, ease of access was the primary consideration, and for some a central location was more convenient as they worked or lived near the city centre,

I: ‘So for you the hospital is more convenient?’

P2: ‘And cheaper.’

I: ‘Than catching the bus.’ (2, male, refugee, lives in the inner-city, no transport)

The majority found PCDS to be acceptable for reasons of avoiding some perceived disadvantages of hospital-based care at a central location such as limited or expensive car parking and long waits for their appointment once they had arrived. When asked about preferences for local provision of care, participants equated this with their own locality. Services provided in a primary care setting are generally only local to residents of that particular area, and for others perceptions of convenience depended on a well-planned public transport system.

Discussion

To date there has been no exploration of preferences for care with UK dermatology outpatients, though satisfaction with tele-dermatology services or care from a specialist dermatology nurse has been researched.^{16–18} This qualitative study provides insight into the findings of the discrete choice experiment, which quantified the trade-offs made by patients requiring access to

specialist advice about skin problems, between quality indicators such as speed of access, specialist status of the clinician, quality of the consultation and convenience of location.¹²

The study explored the views and experiences of men and women with a range of non-urgent skin complaints referred to hospital outpatients or a GPSI. Participants mainly welcomed the GPSI if this led to shorter waiting times without reduction in health outcome. However, for some people a GPSI service would be less acceptable. These are likely to be patients with experience of painful or longstanding conditions unsuccessfully treated by their own GP. Furthermore, participants with a hierarchical understanding of medical expertise, who identified the hospital consultant as the top of their field, were also likely to be less happy with a referral to a GPSI. These findings, though not necessarily transferable, may have implications for health services planners.

There is evidence that patient satisfaction and adherence to treatment is related to the quality of the communication between practitioner and patient.^{19,20} Some participants commented on their GP’s apparent lack of appreciation of the problems of managing their skin condition, leading, they felt, to reluctance to refer. It was significant that in some cases it was not the usual doctor who referred for a second opinion, perhaps relating to the patient feeling more at ease in asking for a second opinion, or highlighting the value of a fresh look at a chronic problem in general practice. However, participants were more forgiving of a cursory examination or interview by a consultant, considering these shortcomings an acceptable trade-off for their perception of the greater knowledge and expertise a hospital specialist could offer.

Implications for change in service delivery

Patients may not always accept changes in service delivery easily, even when satisfied with a new service. One participant who experienced, and was satisfied with her appointment with the GPSI, clearly expressed a preference for consultant-led care for future consultations. It may be that this attitude owes more to familiarity with the old rather than distrust of new services. However, other studies have found that where one practitioner substitutes for another, regardless of equivalent quality of care and greater satisfaction, patients state a preference to be seen by the former practitioner were they to be in the same circumstances again.^{21,22}

In this study GPs assisted patients to make health-care choices. A number of participants chose to attend the PCDS because their GP advised there was a lengthy wait to be seen at the hospital. Current policy encourages

GPs to support eligible patients in making choices about accessing healthcare services,²³ and it is important to recognise how GPs can influence their patients by their use of language to describe services; avoidance of terminology such as 'top man' that suggests value judgements in the relative expertise of practitioners in dealing with comparatively minor skin conditions could encourage some suitable patients to use the service provided by the GPSI.

Since hospitals are usually centrally located, a primary care location is likely to be local for a minority of secondary care users only. However, shorter waiting times, ease of parking and access by public transport are likely to offset inconveniences such as distance. The location chosen for a PCDS is important, as for most potential users it is unlikely to be local to their home or work. About half the participants in this study lived in a somewhat rural location and were used to travelling comparatively long distances for their hospital services. These participants valued the ease of free parking and were not unduly dismayed by the journey, but many commented that such a service should be positioned on a main road. For participants without ready access to a car, poor public transport constituted a barrier necessitating a long and slow journey.

Limitations of the study

The study was confined to patients with skin complaints referred for routine outpatient appointments only. Letters of invitation for interview were included with the patients' booking letters, but due to a high hospital clerical staff turnover and workload it was not possible to be sure invitation letters were always included, making the response rate uncertain. However, sampling proceeded over a number of months and data saturation was achieved. With regard to transferability, the study described the experiences of self-selected volunteers, though purposive sampling within the group who agreed to be interviewed ensured an even spread of age, sex, presenting symptoms, proximity to the service, and those who had experienced care compared to those who had not.

Conclusion

Although not life-threatening, GPs should be aware of the considerably impaired quality of life experienced by patients with chronic skin complaints. Some participants with minor skin complaints expected more surgical procedures to be carried out by their family doctor. GPSI services were acceptable to the majority, however, there is likely to be a group of patients with longstanding or painful, though clinically non-urgent, conditions for whom the service will not be acceptable.

ETHICS APPROVAL

Ethics approval was obtained from United Bristol Healthcare Trust Local Research Ethics Committee.

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CONFLICTS OF INTEREST

None.

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Appendix 1: interview schedule

(The exact content and order varied according to responses)

1 Can we start with talking about the time when you first had the problem with your skin?

Further probes to explore participant's perception of the severity of the skin condition, the amount of trouble they are having, understanding about the condition and health care sought and received.

2 How much improvement to your skin are you expecting as a result of your GP referring you to the hospital?

This will probe the extent to which a good clinical outcome is important for the success of the consultation.

3 If it were possible to choose where you received your care, between a hospital location and a local setting such as a health centre, where would you want to receive it? Why?

This question will explore aspects of care and access considered important by the interviewee. Probes will explore the importance of pros and cons raised by the patient.

4 What do you like about getting care from the hospital?

For example, this will probe the perceived importance of specialist equipment, consultant or specialist care and importance of location.

5 What don't you like about getting care from the hospital?

Probes will check the length of time thought acceptable to wait for an appointment, the length of waiting time once a patient has presented for an appointment, transport links and ease of parking.

6 Some people may be able to receive their care from a specialist GP and nurse at a local health centre. What do you like about that idea? What don't you like about that idea?

The following questions were added to help define and refine attributes associated with access to health care identified by earlier informants, after 15 interviews had been carried out:

7 Some people have told us that the most important thing about getting care for their skin complaint is the convenience of the service. What do you think they would mean by 'convenience'?

8 Some people have told us the most important thing about their care is the opportunity to see an expert, while others have said the quality of their consultation is the most important thing. What would you say is most important to you about the care you receive for your skin complaint?