

Responses from PSALV questionnaire 2008

Introduction

PSALV/Psoriasis Scotland is a peer led Scottish charity for people with skin psoriasis and/or psoriatic arthritis. Membership is open to people of all ages. In 2007, PSALV petitioned The Scottish Parliament's petition committee for the development of a guideline for psoriasis and psoriatic arthritis of 700 signatures on-line.

Many members and enquirers have reported high levels of dissatisfaction about their health care. In order to gauge whether this was reflected by a wider sample of people with psoriasis or psoriatic arthritis, a short questionnaire was designed by Janice Johnson, PSALV and disseminated in 2008.

Method

Members (N=120) were sent a postal questionnaire to seek their views on a small range of issues, related to the referral pathway. There were no reminders.

The responses were analysed using a thematic analysis of key questions from the survey.

Results

Although few responses (n=13, 11%) were received they were helpful in providing some evidence of a range of views from patients with psoriasis or psoriatic arthritis, living in Scotland.

Respondents' characteristics

Number of respondents: 13

Gender	%
Male	42
Female	42
Missing values	14
Total	100

Is your psoriasis...	%
Mild	25
Moderate	0
Severe	67
Missing values	8
Total	100

Is your psoriatic arthritis.....	%
Mild	8
Moderate	0
Severe	8
Not present/diagnosed	25
Missing values	59
Total	100

How would you rate your GP's knowledge about psoriasis?	%
Excellent/good	42
Little	50
Not at all	8
Missing values	0
Total	100

Were diagnosed by your GP?	%
Psoriasis: Yes	58
Psoriasis: No	25
Psoriatic arthritis: Yes	8
Psoriatic arthritis: No	8
Missing values	16
Totals are more than 100 as participants responded to 2 condition in same answer	

Were you treated quickly by your GP?	%
Psoriasis: Yes	33
Psoriasis: No	50
Psoriatic arthritis: Yes	8
Psoriatic arthritis: No	8
Missing values	16
Totals are more than 100 as participants responded to 2 conditions in same answer	

Were you offered information by your GP?	%
Psoriasis: Yes	8
Psoriasis: No	75
Psoriatic arthritis: Yes	0
Psoriatic arthritis: No	8
Missing values	16
Totals are more than 100 as participants responded to 2 condition in same answer	

Did your GP discuss different options for treatment with you?	%
Psoriasis: Yes	8
Psoriasis: No	75
Psoriatic arthritis: Yes	0
Psoriatic arthritis: No	8
Missing values	16
Totals are more than 100 as participants responded to 2 condition in same answer	

Were you referred to secondary care as quickly as you required?	%
Psoriasis: Yes	42
Psoriasis: No	58
Psoriatic arthritis: Yes	0
Psoriatic arthritis: No	8
Missing values	16
Totals are more than 100 as participants responded to 2 condition in same answer	

Qualitative responses

How would you describe the process of your diagnosis?

Respondent 3

'I have had psoriasis for 50-odd years and only learned about it at one of your meetings [PSALV]. My skin has been better since then.'

Respondent 5

'I was diagnosed 20 years ago....the explanation and treatments I was given was very poor.'

Respondent 7

'I had a number of spots in my groin which eventually got bigger and bigger. I had been to my surgery....for an emergency appointment, but they did not say what was wrong! Antibiotics did not make me feel better, in fact I got worse! I phoned NHS 24 explaining everything..... but to no avail. I was getting much worse [and] phoned again NHS 24 but they were hopeless. So, my sister decided to take me to casualty.... And I saw another doctor. She did not know what was wrong with me. By this time I was climbing the walls. I was very distressed and frightened. Another consultant asked me all that had happened but he did not know, but had a word with another consultant and she asked if I would go to see her in another hospital. She was the 5th consultant and she knew right away. So, it took 5 doctors to diagnose that I had pustular psoriasis. I would not wish to anyone what I had gone through, so I personally think that [it] is very, very important for at least one doctor in every surgery in the country to have a thorough course on psoriasis.... Because really I had gone through hell! Sorry to be so blunt!'

Respondent 12

'My psoriasiswas never really diagnosed and explained by GPs. Have never been referred or seen by dermatology to this day. Psoriatic arthritis was totally missed by GPs and was only diagnosed by orthopaedic consultant when I was referred to him with a 'suspected broken finger' and he immediately recognised my nail change due to psoriasis and this associated 'sausage finger.'

Respondent 13

'Around the age of XX, I began to experience pain in my right foot. Over the next 2 years I attended the doctors on numerous occasions but they were unable to tell me what was causing the pain. I then decided to go to a private chiropodist who X-rayed my foot. I took this to my own doctor and when he saw it he sent me to the hospital for further X-rays. It was only then that they discovered that it was arthritis. It was a further 2 years before they diagnosed it as psoriatic arthritis.'

Respondents' views on concordance/discussion of options

Participant 3

'Here, take this ointment!'

'No explanation of what it is, or options for treatment or simple things one can do for yourself.'

Participant 4

'Treatment options....[were discussed at the] skin/rheumatology clinics.'

Participant 6

'I have been well informed about all the various treatments.'

Participant 7

'I was never told [of treatment options]..by my own GP, until I went to the dermatologist.'

Participant 12

'No information was offered and treatment options were never discussed by GPs. DMARDs were prescribed with very limited patient information and no GP explanation of why he was prescribing it or possible side effects. Since being referred to rheumatology, all options were explained by consultant, with most options being tried and finally being prescribed XX for psoriatic arthritis, nothing other than topical treatments for psoriasis.'

'I am fairly knowledgeable now, however this is mainly due to researching by myself. [I] find primary care virtually 'useless' in this respect.'

Participant 13

'Sometimes the GP does not even examine me, they usually ask what I normally use for psoriasis and they prescribe it. They are rarely interested in the extent of the disease or whether it is getting worse. I cannot recall a time when i have ever been asked if the psoriasis is having an impact on my day-to-day life.'

Respondents' views on their referral to secondary care

Participant 3

'By the time I got to see a specialist (12 weeks) the worst was over. That was the first specialist I had seen since 1954.'

Participant 6

'I attend [hospital] every 8-12 weeks. My consultant is very good.'

Participant 10

'Very lengthy wait for hospital appointment, therefore requested private appointment with dermatologist (when necessary).'

Participant 11

'[Referred] eventually, at dermatology by the consultant, was offered ointments etc very little else and eventually given UVB.'

Participant 13

'My specialist has been really great. He has arranged an appointment with the orthopaedic department. I now have an open appointment for 2 years.'

Respondents' views of the psychological effect of psoriasis

Participant 9

'I feel the psychological effects of living with psoriasis is not recognised.'

Participant 11

'I feel the mental health affects of [the] disease are completely ignored. I feel very strongly that mental health is always left aside.'

Respondents' views of the financial burden of psoriasis

Participant 9

'As a pensioner on a very limited income, it can be a serious drain financially; 3 baths a day; constant washing of clothing and bedding; replacing stained clothes ruined by greasy ointments and emollients. No financial help is available if you apply when over 60 years. If under that age, you may get a small financial award. This surely is anomalous.'

Participant 11

'I do feel that financial services are the stumbling block.'

Respondents' views on raising awareness

Participant 9

'Public awareness and acceptance of the disease is still a problem.'

Participant 11

'Please ensure that patients have a voice.....'

Participant 12

'I also feel [that] numbers of sufferers within each GP practice should be collated and available to....interested parties. Data could be made available giving [which] drugs/treatments are being prescribed and successful, or otherwise. This data could serve to raise awareness at a local level and bring together fellow sufferers who generally 'suffer in silence and [in] isolation.'

GP training and patient information is key. I have never saw any posters or information leaflets on display in my local health centre.'

Participant 13

'I feel that employers and employees require more training on disability discrimination. Last year I attended a self management course through Arthritis Care. I would recommend this course to others as it helped me.'

Respondents' views on GP knowledge of psoriasis

Participant 5

'My last 2 GPs have been very helpful and knowledgeable about psoriasis.'

Participant 8

'Local GPs seem to treat this with little or no real knowledge.... And at best seem [to] shy away from referencing you to skin clinic. When you ask about new treatments they often refer to manufacturers catalogues for information. Not really what we look for!'

Participant 10

'Most GPs prescribe commonly used ointments – not too knowledgeable about recent developments, probably feel more major issues a priority.'

Participant 11

'GP knowledge is limited, which is fine if they knew the basics. My GP says "know the main points of disease and symptoms, partially palliative care, refer on to specialist services and ensure speedy appointments." I have been unlucky with GPs in the past, but have an excellent GP now.'

Participants 13

'I will never forget what one of my doctors said to me. When I entered his room, the first thing he said to me was "hello, cripple!" I was very young at the time

*and I remember saying, "Don't call me that!" I was really upset when I left/
Straight away I changed my doctor.'*

Respondents' knowledge

Participant 12

'[I am] fairly knowledgeable now, however this is mainly due to researching by myself. [I] find primary care virtually "useless" in this respect. GP training and patient information is key. I have never saw any posters or information leaflets on display in my local health centre.'

Participant 5

'PSALV is a great source of information to me.'

[Analysis by Dr Lorna W McHattie, The School of Pharmacy and Life Sciences, Robert Gordon University, Aberdeen.]

Conclusions

The response rate was disappointingly small (11%), although this was our first attempt at surveying our membership.

Nearly 60% of respondents felt their GP's knowledge of psoriasis was "little or nil" guideline for psoriasis and psoriatic arthritis. This received a response and even less for PsA.

75% of respondents said their GP offered no information on their conditions, or on treatment options.

Although it is acknowledged that generally people who respond are more motivated if they hold strong views (negative or positive) about the subject under investigation, there are key messages which are especially poignant:

1. Difficulties of diagnosis are common. One participant reported that their pustular psoriasis was failed to be diagnosed by four doctors. This is a potentially life threatening condition and the consequences of lack of GP knowledge could have been fatal.
2. There seems to be inconsistency of movement between primary and secondary care.
3. Participants want more information to help them make informed choices with their doctor. This is concordance.

Report by Janice Johnson for PSALV
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