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Assessing Comorbidities, Quality of Life, and the Needs of Patients with Psoriasis and Eczema at Each Consultation; Can Their Needs be Assessed and Met Online?

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ABSTRACT

Background: Research showed that patients with psoriasis and eczema often suffer from comorbidities and their needs are not always assessed or met. **Objective:** The objective of the study was to develop an assessment tool to address the needs, comorbidities, and feedback of patients with psoriasis and eczema and to obtain their view on using the tool. **Methods:** A mixed-method research included a quantitative (postal survey) and a qualitative (face-to-face interview) to capture patients' opinions and feedback. **Results:** In the postal survey, the majority (95%) of the participants reported physical, metabolic, and psychological comorbidities. Almost 30% of them stated that they could not cope with their chronic skin disease and 10.5% had depression and suicidal thoughts. Around 24% of them expressed the need for support at home and 14% asked for support at work. All the interviewed participants agreed that the regular use of the study tool can address their needs and enhance their competence to self-manage their illness. **Conclusions:** The new study tool disclosed heterogeneous information on patients' needs, management barriers, and comorbidities. Regular use of the tool at each consultation was welcomed by all the interviewed participants as it can fill important gaps in their management and in service improvement.

Key words: Assessment tool, comorbidities, eczema, needs, portal system, psoriasis, quality of life, self-management, survey

INTRODUCTION

Skin diseases can profoundly impair general well-being and self-respect, posing a real threat of issues with mental health, leading to severe depression and even suicide.^[1,2] Patients with eczema and psoriasis are susceptible to long-term comorbidities that have a further impact on quality of life (QoL).^[3] Their relationship with the healthcare provider may last for years, and despite the longevity of these relationships, many of the personal, psychological, and economic strains experienced by the patients go undisclosed.^[4] Patient's feedback data from

routine clinical practice are found to be useful in health care cost-effectiveness research and in improving the quality of the service.^[5] However, the limited physician consultation time leaves patients with a finite opportunity to address their needs, comorbidities, and feedback on the service they received.^[6]

Health information technology tools such as eHealth and patient portal systems (PPS) have been adopted by many health care organizations since the late 1990s to enable patient-provider communication.^[7] We conducted a postal survey on patients with psoriasis and eczema using the study tool in the form of a questionnaire. The survey was followed

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by interviewing patients who participated in the survey to understand their needs and to capture their opinions on using the study tool or its online version at each consultation to address their needs and comorbidities.

METHODS

Participants

This is a two-step mixed-method exploratory study. The first phase of the research included a postal survey assessing the needs, views, and comorbidities of patients with psoriasis and eczema using the study tool. The tool consisted of a questionnaire that contained a dermatology life quality index (DLQI) and 8 supplementary open-ended questions to enable patients to express their views, needs, coping mechanisms, and comorbidities and to elaborate on different aspects of their care. In December 2017, a pilot study was conducted on 23 patients with psoriasis and eczema in a dermatology department of one of the National Health Service (NHS) hospitals in England. In January 2018 and for 3 months, a postal survey was conducted on adult patients with similar skin diseases and managed by the same hospital. The study's patient information sheet, study tool, and self-addressed envelope were posted to 482 consecutive eligible patients. The inclusion criteria were broad, with adult male and female patients with psoriasis or eczema aged 18 years or older and able to provide consent, read, and understand the English language. The patients who agreed to participate in this study were asked to fill out and post back the study tool to the same hospital.

The second phase of the study included an audio-recorded face-to-face semi-structured interview with 22 patients who had participated in the postal survey. Written informed consent was obtained from each participant before the interview. The interview was focused on understanding patients' needs and to capture their view on using the study tool or any other alternative tool at each hospital consultation and preference of using PPS. Patients in this study had no access to a PPS. Their opinions were based on hypothetical PPS. They were interviewed in the same hospital where the pilot study was conducted. Verbatim transcript and a coding process were used. No funding was received for this study and no incentive was offered to the participants. The study printing materials and postage costs were covered by the sponsored hospital. Ethical approval for the above studies was obtained locally and nationally. All the materials used in the research were processed, managed, and stored in line with the general data protection regulations of 2018.

Data analysis

The data obtained from the survey were transferred into a spreadsheet after comparing each participant's response with his/her hospital notes and were analyzed by gender, age, comorbidities, topical treatment preference, patient feedback

on the service received, patient coping mechanisms, patient needs, disease triggers, and by the DLQI score. The latter index contains 10 questions and is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The higher the score, the lower the patients rating of their QoL.^[5]

All interviews were transcribed and thematically coded after comparing the similarities between participants' responses. Both studies were conducted and analyzed by one researcher and regularly reviewed by two academic supervisors.

RESULTS

Postal survey results

One hundred and fourteen patients (including all the volunteers in the pilot study) participated in the postal survey. Thirty participants (26.3%) had eczema, and 84 (73.7%) had psoriasis. The female/male ratio was 58/56. The age range was between 18 and 88 years and the average age was 51.2 years. Of the 391 patients who did not participate in the postal survey, 101 (25.8%) had eczema and 290 (74.2%) had psoriasis. Their female/male ratio was 195/196 and they had a similar age range, but with an average age of 44.4 years [Table 1].

Comorbidities were present in 95% of participants, as follows: 45.6% had joint pain or arthritis, 22.8% had high blood pressure, 15.7% had high lipid profile, 14% had poor mobility, 12.2% had diabetes, and 11.4% were obese. Psychologically, 28.9% could not cope alone with their chronic skin disease, 16.6% were unable to deal with the stigma of their skin disease, 16.6% had insomnia, 15.7% were suffering from anxiety, 10.5% had depression and suicidal thoughts, and 8.7% have no family support [Figure 1].

Stress was the dominant disease triggering factor in 63.1% patients, and the cold weather was the second most common trigger in 45.6% patients [Table 2]. The coping mechanisms reported by participants to deal with their chronic skin disease were; watching TV or listening to music for 55.2% of participants, comfort eating for 24.5%, practicing hobbies for 17.5%, practicing religion or praying for 16.6%, working late

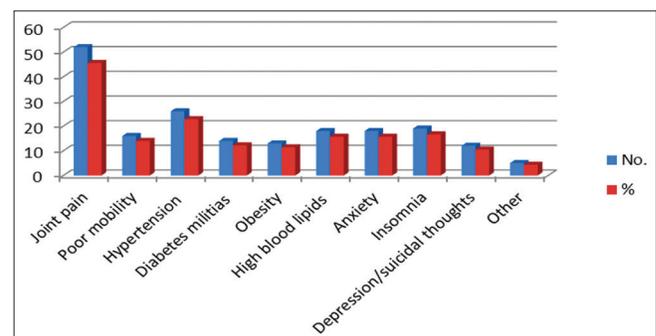


Figure 1: Participants' comorbidities

Table 1: Participants characteristics and their DLQI score in the postal survey (n=114)

Total patients invited to participate in the study	505
Total patients agreed to participate	114
Female/male ratio for participants	58/56
Female/male ratio for non-participants (n=391)	195/196
Mean age for participants	51.2 (range 18–88 years)
Mean age for non-participants	44.4 (range 18–88 years)
Psoriasis/Eczema ratio for participants	84/30
Psoriasis/Eczema ratio for non-participants	101/290
Participants used topical treatment	107
Participants used systemic and topical treatment	33
DLQI range for participants	0–26
Mean DLQI for male participants	8.45
Mean DLQI for female participants	8.1
Mean DLQI in eczema participants	10.7
Mean DLQI in psoriasis participants	8.29

DLQI: Dermatology life quality index

hours for 5.2%, using antidepressant medication for 5.2%, reading for 4.3%, socializing for 4.3%, and practicing sport for 3.5%. Other mechanisms were used by a smaller number of participants; talking to friends, making self-busy, trying to ignore it, sleeping, walking the dog, and using fidget spinner.

The DLQI score of participants ranged from 0 to 26 and 37% was scoring more than 10. Five of those who scored more than 10 were receiving systemic therapy, including biologics. The average DLQI for male participants was 8.45 and for female participants was 8.1, while the average DLQI in eczema patients was 10.7 and in psoriasis patients was 8.29 [Table 1].

As for patients' needs, 45.6% participants asked for more and longer appointments with their dermatologist, 26.3% asked for more and longer appointment with their GP, 25.4% requested for more health information, 23.6% asked support at home, and 14% of them requested support at work [Figure 2]. Around 18% of participants rated the service they received from their GP as poor, and further 3.5% participants rated it as very poor, while 7.8% participants rated the service

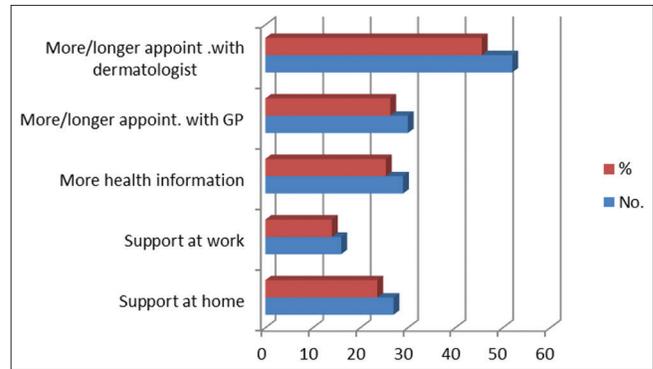


Figure 2: Participants' needs

they received from their dermatologist as poor and further 2.6% participants rated it as very poor.

The majority of participants (93.8%) were using topical therapy for their skin disease and 38.5% felt that such a therapy was inconvenient to apply as frequently as is recommended, 33.3% of them found it ineffective, 28% participants stated that a repeat prescription of topical therapy was not easily accessible, 10.5% felt that topical therapy makes their skin worse, and 5.2% participants did not know which one to use and how frequently [Table 2]. There was a contradiction in patients' views regarding the effectiveness of topical treatment. Around 8% participants found that Dermovate ointment was helpful, while 3.5% found it unhelpful. Similarly, 4.3% participants found that Dermol cream was helpful, while 2.6% found that the same cream was unhelpful.

Almost 29% of participants were on systemic therapy, including biologic therapy. Notably, 44.7% of participants had tried alternative therapies to improve their skin condition: 21% tried a special diet (e.g., gluten-free or dairy-free), 16.6% tried homeopathy, 14.9% tried Chinese herbs, 9.6% tried acupuncture, 6.1% tried yoga and meditation, 5.2% tried cognitive behavior therapy (CBT), 4.3% tried mindfulness, 2.6% tried positive thinking, and one participant tried hypnotherapy [Table 2]. Although some patients found that alternative therapies did ease their distress or enable them to cope with their chronic disease, others thought that such therapy could make their skin rash worse.

Interview results

Twenty-two participants were interviewed. Female:male ratio was 10/12. Mean age 50.09 years. Three patients had eczema and the rest had psoriasis. Table 3 shows the demographics of the interviewees. Coding of their transcripts synthesized 5 themes and 19 subthemes [Figure 3].

All the interviewees (n = 22) found that answering the questionnaire (study tool) was easy to fill out and helpful for the patients and for the physician:

Table 2: The feedback of 114 participants in the postal survey

Participants' view on topical therapy	n	%
Participant found topical therapy inconvenient	44	38.5
Participant found topical therapy ineffective	38	33.3
Participants found repeat prescription was difficult to access	32	28
Participants who felt that topical therapy made their skin rash worse	12	10.5
Participants who do not know which topical therapy to use	6	5.2
Other patients' comments on topical therapy	Sticky, GP reluctant to prescribe hospital topical treatment recommended by the dermatologist, ointments/creams provide short improvement and work slowly	
Helpful topical treatment for some participants	Hydromol oint*, Dermovate oint, Dovobet gel/oint, Elocon oint, Diprosalic oint, Enstilar foam, Dermol cream, 50/50 ointment, can't remember	
Unhelpful topical treatment for other participants	All creams, Dovobet gel, Dermovate oint, Dermol cream, Diprosalic oint, E45 cream, aqueous cream	
Side effects of topical therapy	Redness and soreness of the skin, skin irritations, slow improvement, thin skin	
Participants tried other therapies		
Special diet	24	21
Homeopathy	19	16.6
Chinese herbs	17	14.9
Acupuncture	11	9.6
Yoga and meditation	7	6.1
Cognitive behavior therapy	6	5.2
Mindfulness	5	4.3
Positive thinking	3	2.6
Hypnotherapy	1	0.8
Other tried the following therapies	Diet (Neem powder, turmeric, oat bath, Gluten-free diet, dairy-free diet), using non-bio powder, GYM, antidepressant	
Triggers of skin rash flare		
Stress	72	63.1
Cold weather	52	45.6
Other triggers	Central heating, too much sugar, detergent, not enough sun, menses	
Coping with chronic skin disease		
Yes	72	63.1
No	33	28.9
Inability to deal with stigma	19	16.6
Lack of family support	10	8.7

*Oint: Ointment

“I think it would give the dermatologist a better understanding of how it affects us personally.”

“I can write what I want in the empty spaces (of the questionnaire).”

“Everything you need you can put it in, so doctors can read it and aware about our needs.”

“Cumulative clinical knowledge help others and help to improve service quality.”

Table 3: Qualitative study population's backgrounds

Participant number	Age	Sex	Civil status	Disease
1	25	Female	Single	Eczema
2	40	Female	Married	Psoriasis
3	41	Female	Single	Eczema
4	46	Female	Married	Psoriasis
5	51	Female	Married	Psoriasis
6	52	Female	Single	Psoriasis
7	57	Female	Married	Psoriasis
8	60	Female	Married	Psoriasis
9	66	Female	Single	Psoriasis
10	67	Female	Married	Psoriasis
11	20	Male	Single	Psoriasis
12	29	Male	Single	Eczema
13	42	Male	Single	Psoriasis
14	47	Male	Single	Psoriasis
15	49	Male	Single	Psoriasis
16	51	Male	Married	Psoriasis
17	52	Male	Married	Psoriasis
18	52	Male	Single	Psoriasis
19	56	Male	Single	Psoriasis
20	57	Male	Married	Psoriasis
21	63	Male	Married	Psoriasis
22	76	Male	Married	Psoriasis

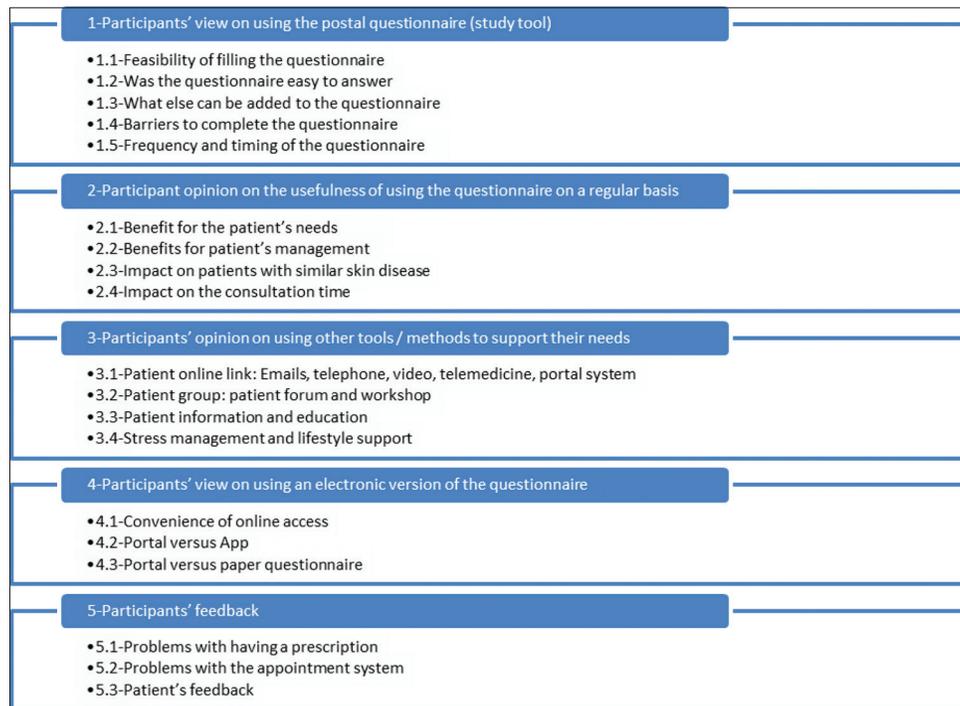


Figure 3: The themes and subthemes generated from interviewing 22 participants

“It is quite emotionally draining having this condition. Asking questions like this (in the Questionnaire) it just gives better overview of the patient.”

Nineteen participants (86%) preferred using the online version of the study tool or PPS were:

“PPS Save time, it can be done at any place without any time pressure.”

“Definitely, portal system, it is little bit easier because everyone on their phone.”

“We are living in such a tech world, so it would be quicker to do it online.”

“If it is online portal then you can save it if you get distracted and then go back and complete it.”

“Portal system is convenient, happy to do it regularly.”

“I forget to bring my medication and don't know which one is bad/good, portal will help me.”

“Portal is paperless; provide update treatment profile, all over the world, help patient to cancel appointment, refill prescription, give non-bias feedback and without pressure.”

Participants' opinion on the barriers that could prevent them from using the study tool regularly at each consultation was mainly the time. However, they acknowledged that they can fill out the questionnaire any time in between their follow-up visits.

Participants' comments on using alternative tools or methods to support their needs:

“Patient forum where you meet other people.”

“Support group and you can talk about your condition.”

“May be online video telemedicine.”

“Posters information on site saying about skin diseases”.

“Local workshop and giving leaflets in different languages for awareness on treatment.”

“Dermatology nurses can be a source of help to contact with them generally.”

Participants expressed their feelings, needs, and feedback:

“Doctor and nurse never really ask you how skin disease affects your home life.”

“It would be positive thing if the dermatologist asks more question on how we cope.”

“Stress management sessions on the NHS.”

“I am interested to see how much chronic skin diseases affect mental health and relationship.”

“Sometimes the treatment that has been given to me doesn't fit in with my working routine” “Going to work and even sometimes driving can be a pain for me because my skin dry up.”

“I can't cope with stress and it means committing suicide, because I don't think I can cope.”

“Consultation limitation disable patient to express their suffering of daily life, coping level.”

“A bit frustrating is just getting a repeat prescription for a tiny tube of cream or ointment and doesn't last long to finish in few days and it is time consuming to keep asking for repeat prescriptions.”

“It would be interesting to see professional ask a little more about diet.”

“Needs online information on what diet to avoid.”

“Access to appointment booking.”

“I really enjoy swimming but embarrassed by the skin rash, people have asked me if I've had animal bites stings. Wish to have more public information in places like swimming pools etc.”

DISCUSSION

This research used a new tool to assess and support the needs of patients with psoriasis and eczema. The tool disclosed heterogeneous information on patients' views, unmet needs, and unaddressed comorbidities. The findings were congruent with those from previous studies which have found that the effective management of chronic skin diseases is mediated by personal and service limitations and that these can negatively impact on a patient's outcome, productivity, emotional and psychological well-being.^[8,9] Although the national institute for health and care excellence recommended assessing patient's metabolic, cardiovascular, and psychological comorbidities as well as managing the patient's skin rash and arthritis,^[10] the finding of the postal survey identified that metabolic and cardiovascular comorbidities were not always documented in the patients' notes. Stress was reported to be the major triggering factor by participants and reviewing patient's hospital notes; no psychological assessment tool was

used except for patients using biological therapy. A similar failure was reported in previous UK studies; physicians often miss the opportunity to assess the comorbidities under the skin and tend to focus only on managing the visible rash.^[8,9]

Apart from offering a platform for the patients to address their needs and comorbidities, the study tool motivated the participants and enabled them to be actively involved in contributing to the management of their chronic disease. They addressed their symptoms, management barriers, treatment preferences, and appraised the quality of care they received. Such information can determine patient's management outcome and quality of care.^[4] In addition, the study tool identified a poor relationship between some patients and their physicians. Patient/physician barriers can significantly influence the patient's management and compliance with the treatment.^[8,9] Participants also expressed personal and social challenges in living with the stigma of the disease. Lack of public health awareness of skin diseases can subject such patients to different types of abuses.^[4]

The DLQI score in this study did not correlate with the severity of the disease or with the type of treatment received and did not map all aspects of a patient's health, including comorbidities and psychosocial challenges [Table 1]. In contrast, the study tool explored patients' needs and comorbidities and enabled the patients to address their feedback.

The low response rate in postal surveys is common and has been reported in previous studies.^[11,12] In addition, analyzing the results of a postal survey was time consuming and labor intensive. We proposed using the online version instead. The majority of the participants welcomed using PPS as a convenient tool to support their care at different levels. Three participants, however, preferred using a paper questionnaire. Choices of paper or online questionnaire can be offered to diverse population. Further, PPS can be modified to an App accessed through a mobile phone and linked with other supportive services; patient information sheet, patient online forum, access to test results, appointment scheduling, medication refill, link with local mental health, CBT services, and with supportive dermatology charities.^[7]

Furthermore, PPS can be designed to act as a prospective study providing a coding system and unobservable longitudinal data on the natural history and trends of chronic skin diseases as well as regularly screening patients with such diseases for comorbidities at an early stage. The coding and the data generated by the PPS can assist health care organizations in policymaking and resource allocation.^[7]

CONCLUSIONS

Using the study tool was welcomed by all the participants and the majority of them preferred PPS. The tool motivated

patients to be actively involved in decision making and self-managing their chronic disease. It can also provide coding and longitudinal clinical data that may influence their management plan and quality of care. The tool provided a rich ground for designing a PPS. Future studies can evaluate the feasibility of developing PPS in different health care settings.

Limitations

The research did not include the service provider to assess their views, resources, and service limitations and to identify the feasibility and logistics of implementing the study tool within the limited consultation time. The study did not compare the response rate and the effectiveness of using the study tool with using alternative assessment tools. It also did not include children, patients with language barriers, learning or cognitive disabilities, and patients with no internet access. Such patients may have difficulty in understanding or using the study tool.

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