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Phototherapy: the patients' point of view

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Survey in four referral centers in Emilia-Romagna

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Psoriasis is a chronic, relapsing, inflammatory disease affecting 2-3% of the population. It often severely compromises the patient's quality of life. Various types of phototherapy are available, including narrowband UVB (nb-UVB) (311 nm), and photochemotherapy (PUVA), utilizing psoralen and ultraviolet A radiation (320–400 nm).¹ Phototherapy consists of exposure to ultraviolet rays, with a dosage based on the patient's phototype and administered in sessions performed two or three times a week for approximately 10 weeks. Although many other systemic treatments are available, phototherapy is still routinely used as both the first or second-line treatment for patients with chronic plaque psoriasis. It is cost-effective, and particularly for nb-UVB, the associated risks are low.¹ Oral PUVA is more effective than nb-UVB for psoriasis. However, nb-UVB rays are linked to a lower risk of cutaneous malignancy, while they do not require laboratory monitoring and are better tolerated.^{2,3} The therapeutic effect of UVB rays is complex and involves a shift from Th1/Th17- to Th2, which causes a drop in the cytokines such as IL-17, IL-22, and IL-23. Moreover, UVB causes apoptosis of inflammatory cells⁴ and also has effects on the innate immune system, acting on the innate lymphoid cells.⁵ The mechanism of action of PUVA is based on the linkage between psoralen and DNA, causing the interruption of the cell cycle.⁵

The guidelines in Italy envisage phototherapy as the first-line treatment for moderate to severe forms of psoriasis,⁶ permitting cost savings by delaying alternative expensive treatments, such as biological treatments. Phototherapy requires a significant allocation of time and resources. In certain cases this makes it difficult, if not impossible, to perform the procedure adequately and continuously. In this connection, it should be noted that the literature is characterized by a lack of data about the point of view of the patient.

We performed an open label, observational study aiming to investigate patient opinion about phototherapy. For this purpose a questionnaire was devised using the DELPHI method (Figure 1). This study was approved by the local Ethics Committee (n.1139/2019) and was conducted in accordance with the Declaration of Helsinki. We made the questionnaire available to all the psoriatic patients undergoing phototherapy at dermatology clinics in Modena, Bologna, Parma and Ferrara (Italy) from December 2019 to March 2020. The aim of the study was to assess the indirect and social costs incurred by patients undergoing phototherapy.

We enrolled 200 men and 136 women in the study, with a mean age of 54.8 years (range 16-82). Most were in employment (175/336), while the others were students (30), unemployed (32) or retired (99). Narrow band UVB was performed in 222 patients, while PUVA in the others. Patient

satisfaction did not differ significantly between those treated with UVB or PUVA (8.9 ± 1.3 with PUVA and 8.1 ± 2.2 with narrowband UVB). Patients spent an average of 19.89 ± 19.57 minutes to reach the hospital, covering a mean distance of 11.28 km (Figure 2). The total time in minutes to perform a session (63.4 ± 18.68) was about six times higher than the time spent on the session itself (11.5 ± 9.11). Most of the patients used private transport and more than 90% went to the center alone. Although before starting phototherapy in each center an assessment of the distance and time commitment was carried out by the physician, almost 23.42% of patients reported problems at work, 32% required permission from their employer, and 45% had to suspend or postpone the appointment, thus lowering adherence to treatment and resulting in a significant social impact. The average rating that patients assigned to the phototherapy service was 8.6/10, while 154 patients (46%) would have appreciated the chance to receive phototherapy at home (Table 1).

In the wider setting of psoriatic treatment available to date, phototherapy is highly effective in real-world conditions and it is considered a low-cost treatment,⁷ compared to systemic drugs, in particular to biologics. On the other hand, biologics are self-administered by the patient without the need to reach the center several times per week and the follow-up visits can sometimes be rescheduled without undermining its effectiveness. Although some research has been performed, there is no overall evidence that biologics are more effective than phototherapy, in particular nb-UVB, in cases in which the treatment is performed in the correct manner.⁸

Some authors recommend phototherapy as the first line of treatment in patients with contraindications, scarce adherence or lack of response to systemic drugs. In fact, nb-UVB is characterized by a high level of tolerability and safety.^{2,9}

Currently, home phototherapy under medical supervision is not usually performed at our centers, but a number of patients purchased a private nbUVB machine after performing the first sessions at the hospital. To offer a safe home phototherapy service, the physician should ideally provide the patient with appropriate training, along with an accurate dosimetry, nursing support and review during treatment, according to the project developed in Dundee in 2002.¹⁰ It may be supposed that the majority of patients performing phototherapy at the hospital do not have a complete overview of the management of home phototherapy, so it should be used with caution.¹¹ Moreover, Emilia-Romagna is characterized by a temperate climate, including seaside resorts, mountains and countryside, for this reason the phototherapy service is not usually provided from June to September. During these months, psoriatic patients spend a lot of time outside, taking advantage of the temperate climate. However, the phototherapy performed at the center or the home-

phototherapy have the incomparable advantage of delivering the quantity of UV in a controlled manner, and therefore limit the risk of inappropriate exposure in comparison to heliotherapy.

This study highlights the point of view of patients undergoing phototherapy: most of the patients in the study live within easy reach of the phototherapy center and have their own transport.

Phototherapy is an indispensable treatment option for its versatility, cost and effectiveness, though it has limits in terms of the ability or willingness of the patient to dedicate time and to travel to the phototherapy center to receive treatment on a regular basis.

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Demographics						
Patients no. 336	Men: 236 (70.23%)	Women: 100 (29.76%)	Mean age: 54.77±15.96 years			
Work features						
Employed: 110 (32.73%)	Freelance: 65 (19.34%)	Students: 30 (8.91%)	Unemployed: 32 (9.52%)	Retired: 99 (29.46%)		
Phototherapy						
UVBTL01: 222 (66.07%)			P-UVA: 114 (33.92%)			
One session per week: 7 (2%)		Two sessions per week: 241 (71.72%)		Three sessions per week: 88 (26.19%)		
Times and distances						
Time spent	From home to the hospital: 19.89±19.57	Place of departure	Home: 250 (74.4%)	Transport	Public: 73 (21.73%)	
	Waiting time: 5.4±4.82		Work: 73 (21.72%)		Private: 261 (71.31%)	
	Total time for therapy: 11.5±9.11		School: 11 (3.27%)		Both: 2 (0.59%)	
	Time to go back home: 28±17.68		Home or work: 2 (0.59%)	Go to the center alone	Yes: 304 (90.47%)	No: 32 (9.52%)
Total time (min):	63.4±18.68	Distance	Mean: 11.28 km	Median: 10	Min: 0	Max: 60
Quality of life						
Permit	No: 119 (68%)	Work problem	No: 134 (76.57%)	Therapy suspended or postponed	No: 185 (55.05%)	Score 8.6±1.58
	Yes: 56 (32%)		Yes: 41 (23.42%)		Yes: 151 (44.94%)	
Desire to perform phototherapy at home						
No: 182 (54.16%)			Yes: 154 (45.83%)			

Table 1: Results of the survey. Investigated items: demographics, work features, phototherapy, times and distances, quality of life, desire to perform phototherapy at home.

QUESTIONNAIRE ABOUT PHOTOTHERAPY IN THE TREATMENT OF PSORIASIS

1) WHAT TYPE OF PHOTOTHERAPY DO YOU DO?

 PUVA

 NB-UVB

2) HOW MANY SESSIONS DO YOU PERFORM IN A WEEK?

 1

 2

 3

 4

3) WHAT IS YOUR OCCUPATION?

- WORK
- STUDENT
- RETIRED

4) WHERE DO YOU COME FROM WHEN YOU GO TO THE CENTER TO PERFORM THE PHOTOTHERAPY?

- FROM HOME
- FROM WORK
- FROM SCHOOL / UNIVERSITY

5) HOW MANY KM DO YOU DO TO PERFORM THE PHOTOTHERAPY?

(KM)

6) HOW DO YOU REACH THE CENTER?

- PUBLIC TRANSPORT
- PRIVATE CAR

7) HOW MUCH TIME DO YOU NEED TO REACH THE CENTER (TRAVEL + PARKING ETC.) (MIN)

8) TO REACH THE CENTER AND PERFORM THE THERAPY:

- I MUST BE ACCOMPANIED
- I COME ALONE

9) HOW LONG DO YOU WAIT IN THE CENTER BEFORE ACCESSING THE THERAPY?

(MIN)

10) HOW LONG DOES IT TAKE TO PERFORM THE THERAPY (INCLUDING UNDRESSING AND DRESSING)? (MIN)

11) HOW LONG DOES IT TAKE TO RETURN HOME / SCHOOL / WORK AFTER THE THERAPY?

(MIN)

12) DO YOU NEED A WORK / SCHOOL PERMIT TO PERFORM THE THERAPY?

 YES

 NO

13) HAVE YOU EVER HAD PROBLEMS AT WORK / SCHOOL TO SPENT TIME TO PERFORM PHOTOTHERAPY?

 YES

 NO

14) HAS IT EVER HAPPENED TO YOU TO SUSPEND OR DELAY THE THERAPY FOR OTHER COMMITMENTS?

 YES

 NO

17) WOULD YOU LIKE A HOME PHOTOTHERAPY SERVICE?

 YES

 NO

15) HOW WELL DO YOU TOLERATE PHOTOTHERAPY ?(0 = not at all; 10 = very much)

(.....)

16) YOU ARE:

- MALE
- FEMALE
- AGE.....

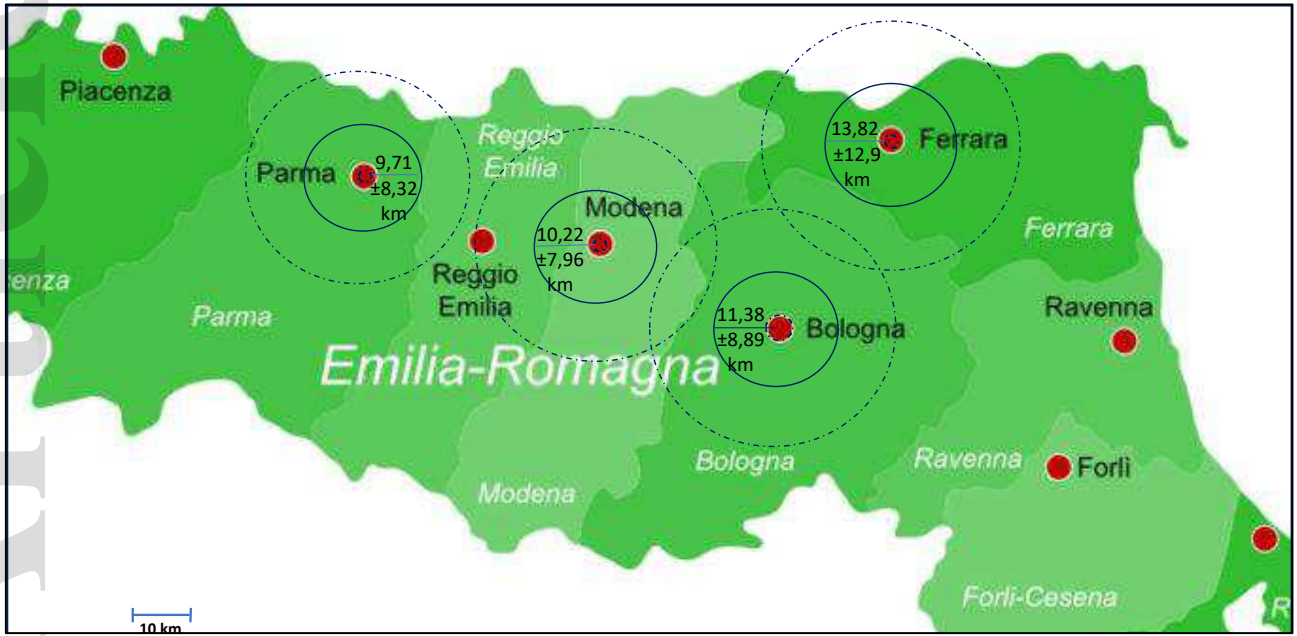


Figure 2: distance (mean \pm DS) from the place of departure to the hospital in the four cities included in the study.