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Patient-Reported Experience Along the Psoriatic Disease Patient Journey in Portugal

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INTRODUCTION

Psoriatic Disease (PsD) is a chronic condition that includes Psoriasis and Psoriatic Arthritis (PsA), affecting the skin, the joints, or both.[1] Due to the different manifestations of PsD, people are often unaware of its systemic nature, symptoms, and associated comorbidities.[2] Patient-focused studies have highlighted the impact of PsD on patients' physical appearance, work, emotions, and relationships.[3] However, the experience and the unmet needs faced throughout of the PsD patient journey remain to be elucidated.

OBJECTIVE

Characterize patients' journey with PsD in Portugal, through patient-reported expectations and unmet needs, from symptom onset to diagnosis, treatment, and follow-up.

METHODS

Based on a targeted literature review, an exploratory sequential mixed methods design was used to characterize patient journey with PsD in Portugal – **1st symptoms**, **1st appointment**, **diagnosis**, **treatment** and **follow-up**. The qualitative phase consisted of a focus group with PsD patients (n=10) focusing on patient's experiences, unmet needs and impact felt throughout each journey stage. The quantitative phase consisted of an online questionnaire targeting Portuguese PsA patient population to quantity the previously collected information in interviews. The questionnaire was shared by members of two national patient's association. The anonymized data was self-reported and collected through an online platform (Qualtrics). **A descriptive analysis of the data collected in the quantitative survey is presented below.**

RESULTS

From March to April 2022, 161 PsD patients (95 PsO, 9 PsA, and 57 both of disease) answered the questionnaire. 61% were female. The average age of participants was 50 (SD=13,6) years and 21% were in the 17-39 age group. The geographical distribution of participants covered 18 districts of mainland Portugal and Azores. The average disease duration (calculated as the difference between current age and age at symptom onset) was 21 (SD=14,3) years. 66% of the participants reported having health insurance/subsystem, 68% reported being employed.

1st symptoms

Average age at onset symptoms was 29 years (SD = 15,0). Although 91% of patient reported onset symptoms associated to PsO, 40% reported the appearance of symptoms associated to PsA at one point in their lives. **17%** of patients reported **high levels** (very and extremely limiting) of **limitations** in their daily life activities, mainly due to symptoms associated to **PsA**. (Figure 1)

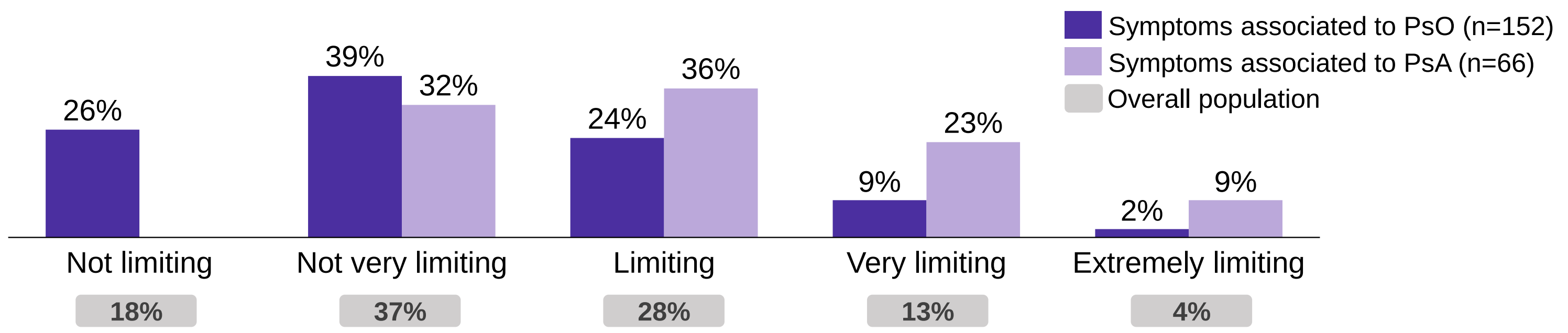


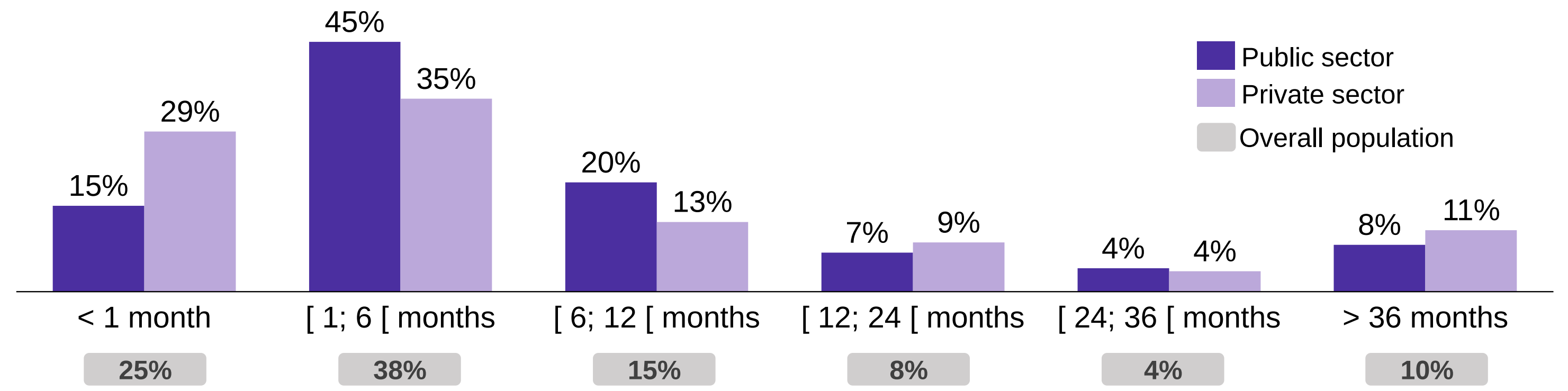
Figure 1. Limitations in patient's daily life activities caused by PsD symptom onset

The onset symptoms had a significant psychological impact on patient's lives, with **75%** reporting **social stigma**, especially societal and work relationships, and **81%** reporting a **loss of confidence and self-esteem**.

The sources of information sought by patients when they experienced onset symptoms were **general practitioners** (43%), **family** (20%), **community pharmacy** (9%), patient's associations (6%), online groups (4%) and work colleagues (2%).

1st appointment

62% of patients reported resorting to the **private sector** for the **first appointment**, mainly to a dermatologist (41%) or rheumatology (13%). In the public sector (33%), general practitioner and rheumatology were the main medical specialties. 6% of patients did not know the sector. Nonetheless, 36% of PsD patients reported **more than 6 months** between symptom onset and resorting to the first healthcare appointments. (Figure 2)

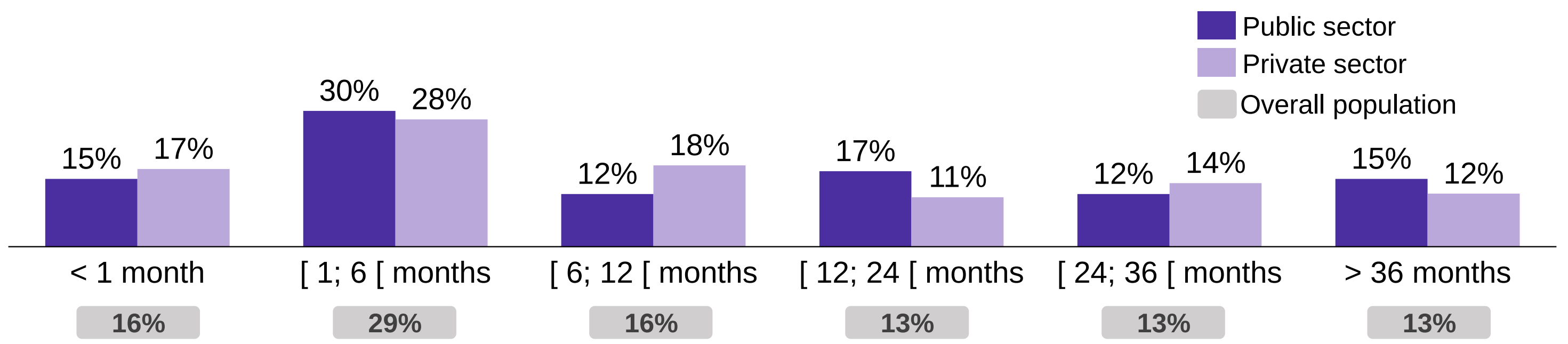


Note: The figure excludes patients who reported not having knowledge about the sector for the first appointment

Figure 2. Time between PsD symptom onset and 1st appointment

Diagnosis

67% of PsD patients reported being diagnosed in private sector, of which 52% by dermatologist and 13% by a rheumatologist. Since symptom onset, 23% of patients reported a period of **more than 1 year to achieve a definitive diagnosis**, with more time reported in public sector compared to the private sector (Figure 3), especially due to **lengthy waiting lists for a specialist appointment.**



Note: The figure excludes patients who reported not having knowledge about the sector for the diagnosis (1%)

Figure 3. Time between PsD symptom onset and diagnosis

Patients shared their expectations of having a timely and precise diagnosis. However, **42%** considered **initial symptoms were devalued by physicians**, **32%** reported initial **misdiagnosis** and **42%** reported not **receiving all the relevant information about the disease at the moment of diagnosis.**

Treatment

Efficacy of treatment, safety and facility to administration were the most valued factors for therapeutic choice among PsD patients. However, 16% reported **not being involved in treatment decision-making.** 48% of patients were on conventional therapies, and 54% of them interrupted therapy by their own decision, especially due to the lack symptom improvement. **40%** of patients were on **biological therapy,** of which **25%** reported **delays in treatment initiation**, mainly due to the COVID-19 pandemic period, lack of hospital approval, and self-doubt regarding side effects of treatment. 85% of patients currently on biological therapy **only started treatment after failing more than one line of conventional therapies**.

71% stated that biological therapy **improved their quality of life** while conventional therapies had less impact, with 44% of patient reporting some, slight, or no improvement in their quality of life. (Figure 4)

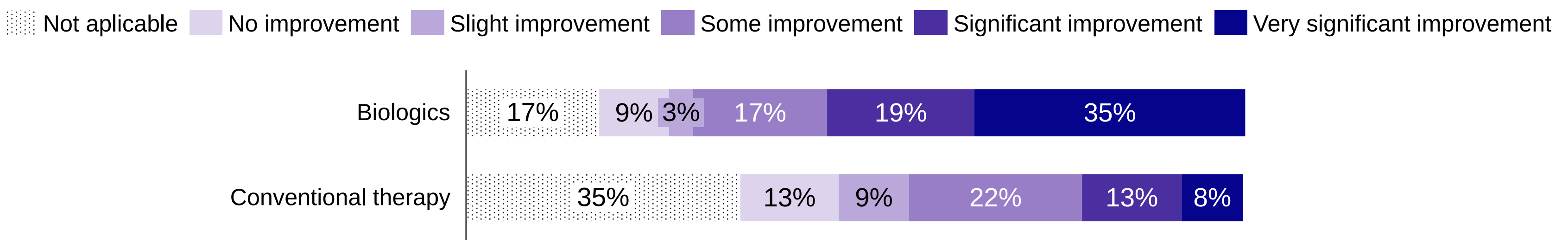
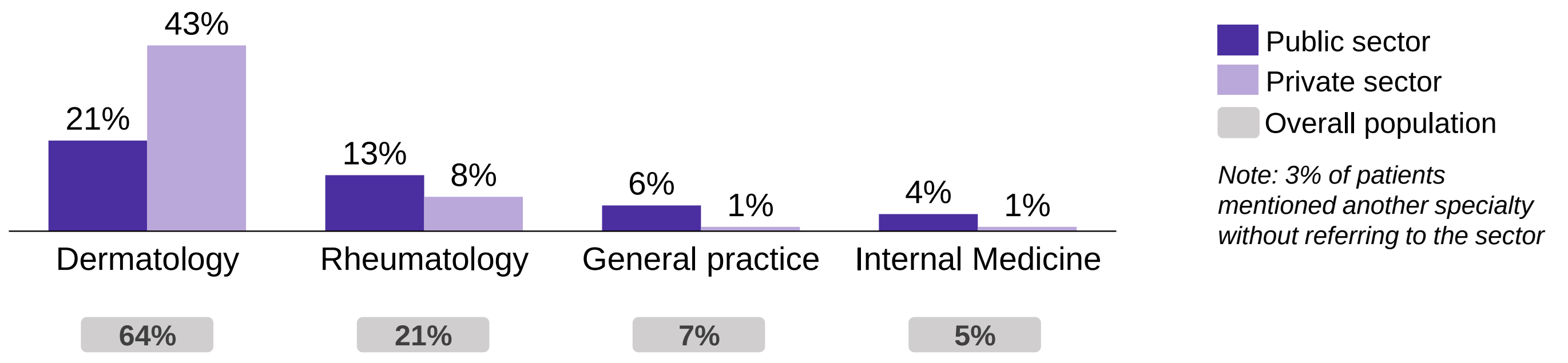


Figure 4. Impact of treatment in quality of life

Follow-up

53% of patients reported being followed in private sector, mainly by dermatologist or rheumatologist. (Figure 5)



Note: 3% of patients mentioned another specialty without referring to the sector

Figure 5. PsD patients follow-up specialties

16% of patients reported having multidisciplinary care at the main hospital follow-up. Nevertheless, **41% reported having to resort, at their own cost**, to additional medical care **outside** of their main healthcare institution.

49% of PsD patients reported an economic burden related to follow-up, especially due to the need for multidisciplinary follow-up care in the private sector (48%) and the need to purchase additional products (80%).

In general, 67% of patients reported **some or a high impact of PsD on their quality of life**; however, the impact is more pronounced in younger age groups. (Figure 6)

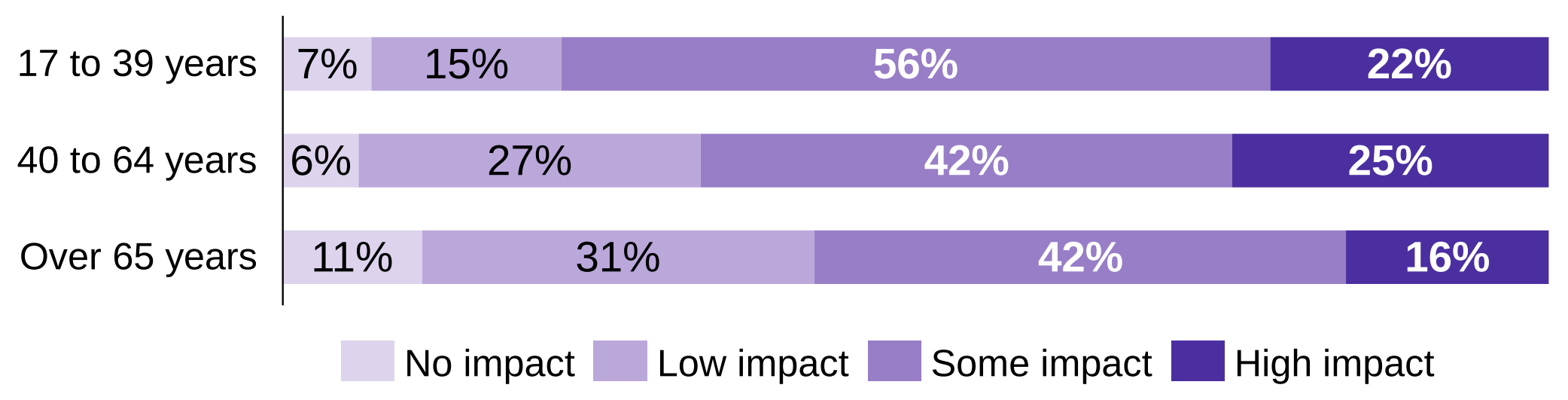


Figure 6. PsD impact in patients' quality of life by age groups

29% of PsO patients reported that they **do not have all the necessary knowledge and tools to properly manage their disease**

CONCLUSION

PsD patients in Portugal face significant barriers in their patient journey. Gaps in disease awareness within society, and general practitioners, coupled with gaps in the healthcare system, translate into delays in diagnosis, access to early-stage treatment, and a lack of integrated follow-up care. These factors lead to an increase in disease-related stigma and psychological burden on patients. Study results can support future patient-centered initiatives, focused on optimizing patient access to healthcare and treatment.

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