

Corticosteroids Usage Impact on Inflammatory Bowel Disease Patients, in Portugal

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BACKGROUND

Corticosteroids are highly effective agents in inducing remission in Inflammatory Bowel Disease (IBD), although studies have demonstrated that they have no role as a maintenance agent (1). Additionally, corticosteroid use has well-documented side effects and prolonged use (often defined as continuous therapy for more than 3 months) can lead to a range of significant morbidities, such as increased risk of infections, avascular bone necrosis, mood disturbances, Cushing's syndrome, hypertension, osteoporosis, among others (2,3). Therefore, it is necessary to understand the impact of this therapy on patient's lives.

OBJECTIVES

- To characterize the corticosteroid usage in IBD patients in Portugal
- To understand the impact of long-term corticosteroid usage in IBD patients' lives, through the assessment of its consequences at a personal, familial, parental, conjugal, social and professional level

METHODS

After a targeted literature review focusing on the long-term effects of corticosteroid usage in IBD patients, a structured questionnaire, validated by a specialist in IBD, was implemented. The questionnaire targeted IBD patients who reported using corticosteroids for the treatment of their disease and/or associated complications. A numeric rating scale of 1 to 5 (1 – no limitation; 5 – severe limitation) was used to assess the impact on the patient's life. The anonymized data was self-reported, collected through an online platform shared by members of two national IBD patient associations (*APDI - Associação Portuguesa da Doença Inflamatória do Intestino, Colite Ulcerosa e Doença de Crohn* and *Associação Crohn/ Colite Portugal*). A descriptive analysis of data collected is presented below.

RESULTS

In June of 2023, a total of 501 people answered the questionnaire, of which 483 had IBD. Among those IBD patients, **437 reported using corticosteroids** for the treatment of their disease and/or associated complications (249 Crohn's disease, 181 Ulcerative Colitis and 7 indeterminate colitis). **The results presented on this study are focused on these IBD patients (n=437)**. The mean age was **41 years** (SD = 11,5). 78% of patients were female and 22% were male. The geographical distribution of participants covered all 18 districts of mainland Portugal and islands. **79% reported moderate to severe disease** and **10% mild disease**. 56% of participants reported having a **health insurance/subsystem** and 78% reported being **employed**.

1. Characterization of corticosteroid usage

The results showed that corticosteroids are mainly prescribed by **gastroenterologists** (95%). 64% of IBD patients reported starting corticosteroids treatment over **4 years ago**, with **43% currently using** corticosteroids, and 18% reported using them for more than 10 years.

Although **70%** of IBD patients reported using corticosteroids only **when symptoms worsen** (during disease flares), **27%** reported **prolonged use** (long-term uninterrupted, with different doses over time).

1.1. Frequency and duration of each corticosteroid usage

35% of IBD patients reported using **corticosteroids three or more times a year**. (Figure 1)

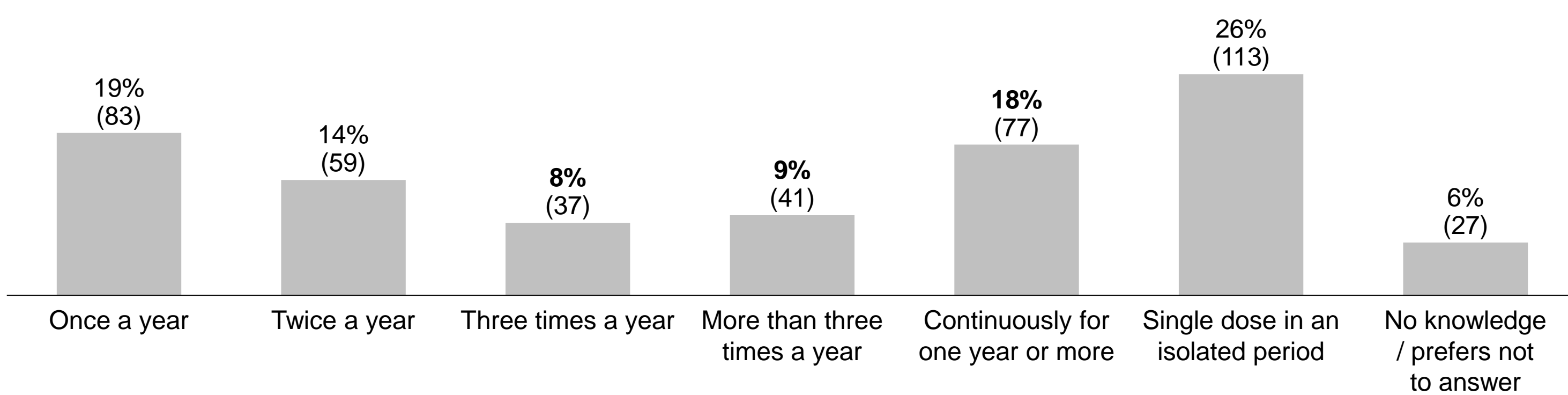


Figure 1. Frequency of corticosteroid usage (number of times)

Considering IBD patients who use corticosteroids at least once a year, **47% reported a duration of each use for more than 3 months**. (Figure 2)

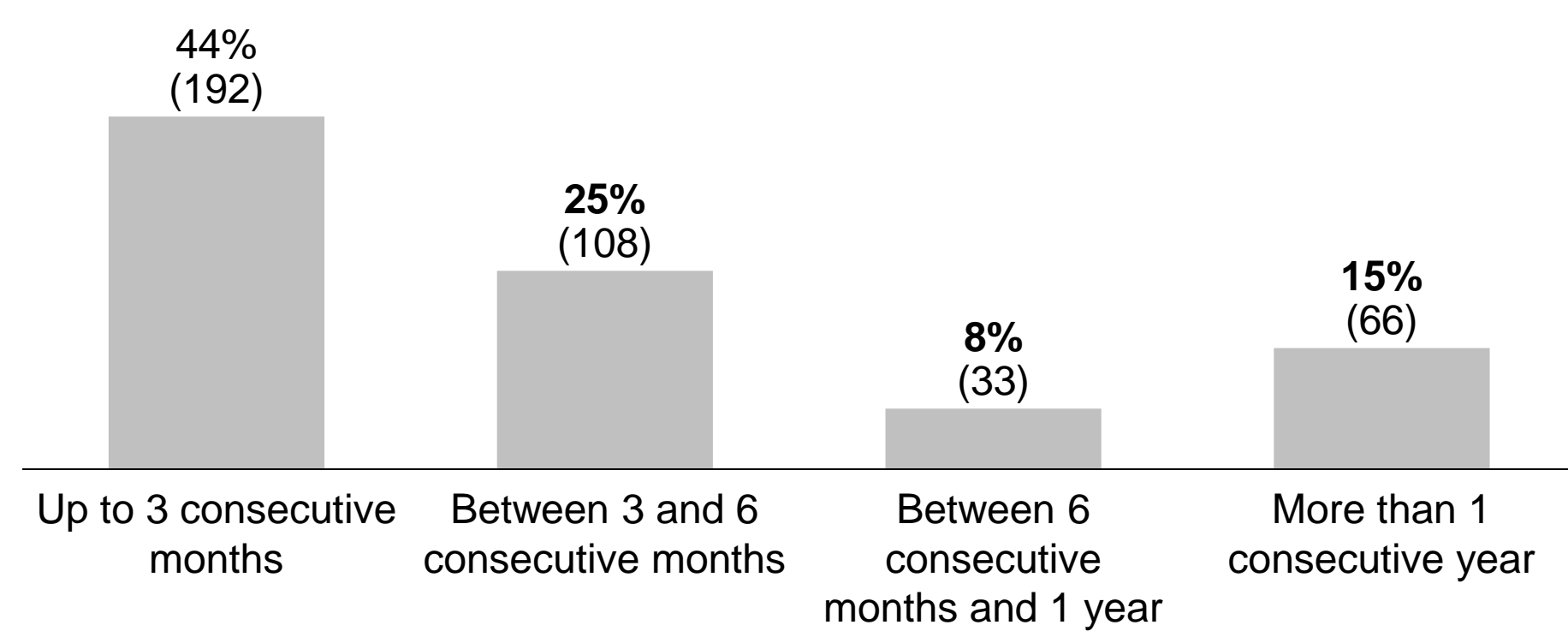


Figure 2. Duration of corticosteroid usage (time of use)

14% of patients who reported corticosteroid usage **only during disease flares**, have an average treatment duration of **3 consecutive months**, with a frequency of **2 or more usages per year**.

7% of IBD patients reported having used corticosteroids without medical recommendation, especially due to disease flares, lack of follow-up appointments and to avoid disease symptoms in specific periods (e.g., work or personal travel).

2. Impact of corticosteroids usage

After starting corticosteroids treatment, 87% of patients developed other complications, namely Cushing's syndrome (57%), behavioural changes (43%), insomnia (39%), skin problems (27%), and osteoporosis (25%)

Specialists are patient's primary source of information regarding the long-term effects of corticosteroid usage. However, **19% of patients reported not having received this information**.

2.1. Limitations in patients' lives

38% of IBD patients reported experiencing limitations in all dimensions of their lives, especially in the **personal, social, and professional** dimensions. Patients who reported using **corticosteroids for more than 3 months** (at least once a year) rated their limitations higher than the patients who reported using corticosteroids for up to 3 months (**44%** versus **32%**). (Figure 3)

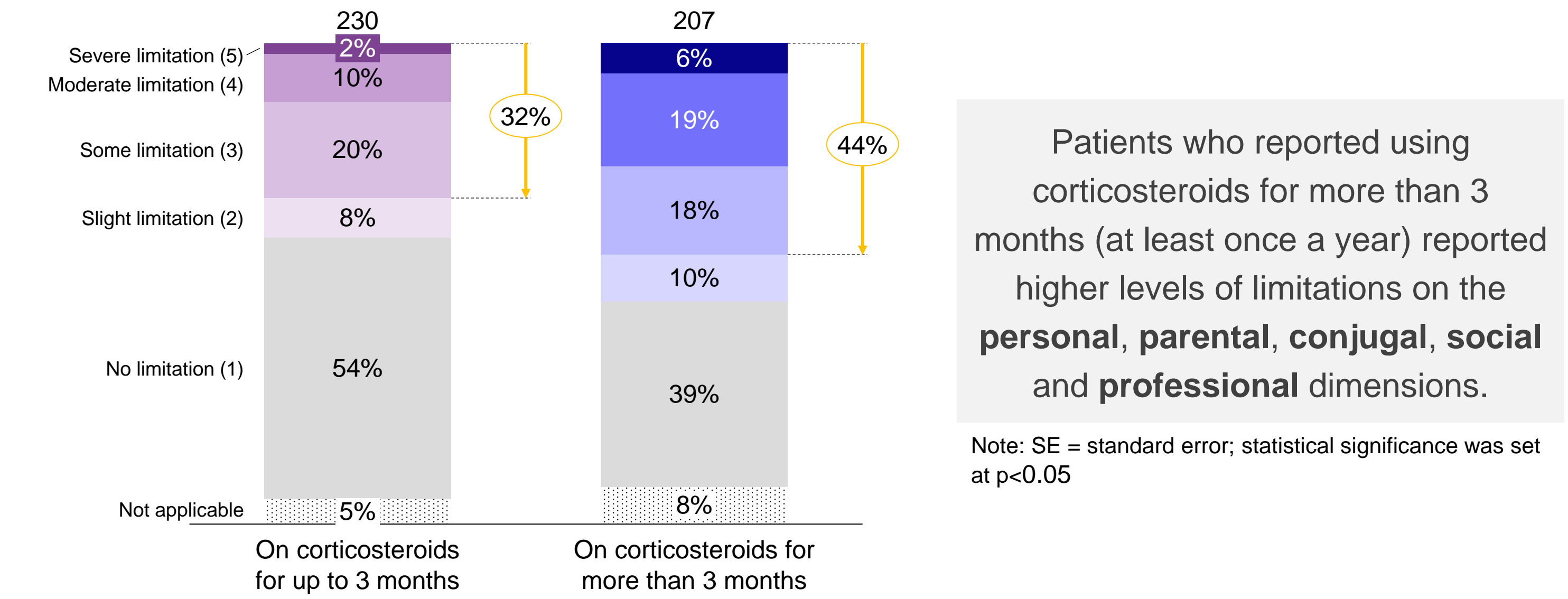


Figure 3. Level of limitations reported by patients in their lives due to the corticosteroid usage

49% of IBD patients experienced psychological impact due to corticosteroid usage, reporting anxiety (63%), sadness (54%), discomfort (47%), incomprehension (43%) and social isolation (38%). Patients who reported using **corticosteroids for more than 3 months** (at least once a year) reported a higher psychological impact than patients who reported using them for up to 3 months (**55%** versus **44%**). (Figure 4)

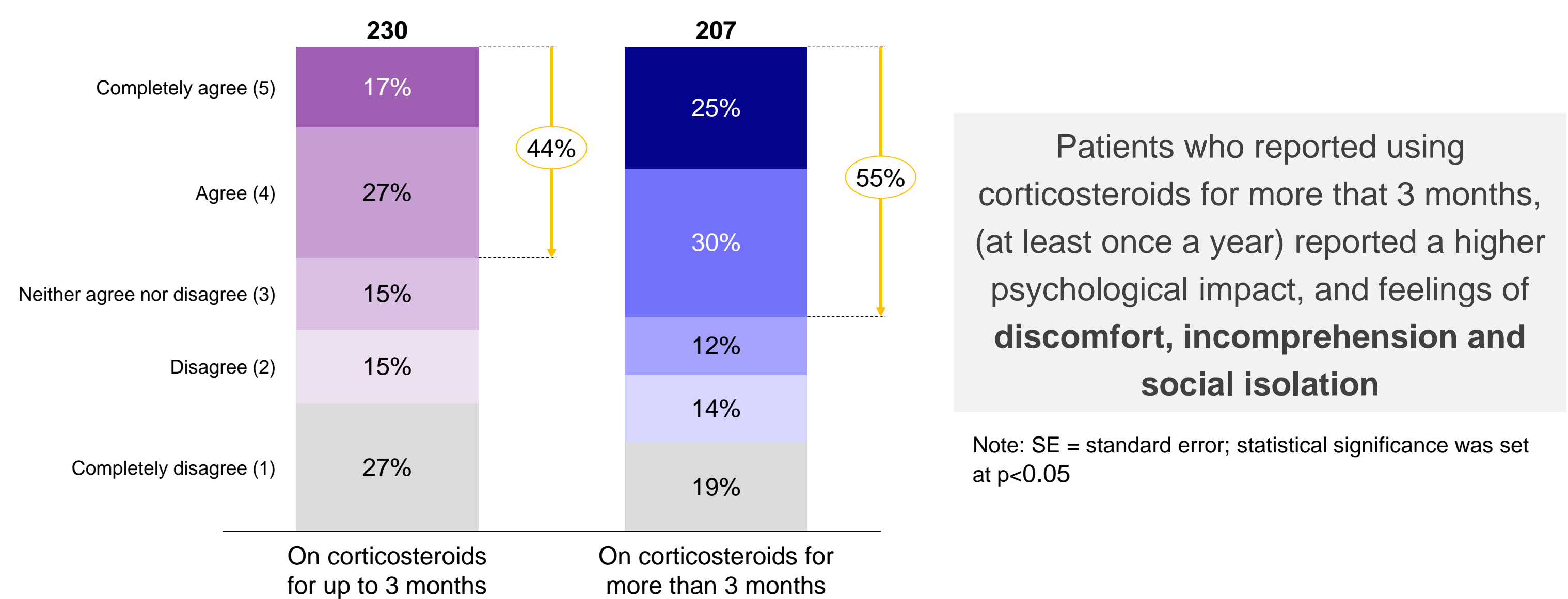


Figure 4. Level of psychological impact reported by patients due to corticosteroid usage

Patients who described prolonged use of corticosteroids reported a higher negative impact compared to those who reported usage only during disease flares, such as loss of **loss of self-esteem** (65% vs. 57%), **social exclusion** (38% vs. 30%), and **missed work/school** (42% vs. 32%). This negative impact is also highlighted when the corticosteroid usage is up to 3 months (at least once a year). (Figure 5)

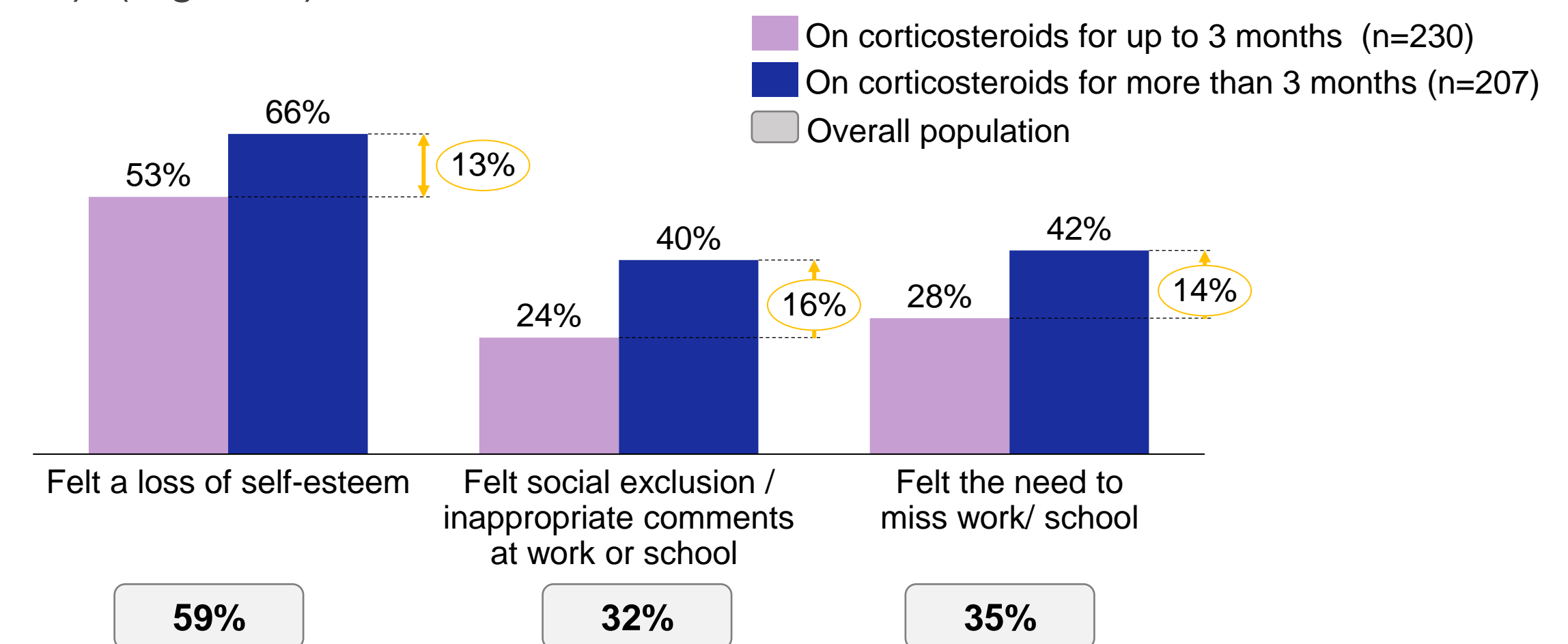


Figure 5. Feelings reported by patients due to corticosteroid usage

74% of patients **discontinued corticosteroid treatment** – of these, 6% chose to do it without medical recommendation, mainly due to adverse effects (42%) and for reasons related to appearance and self-esteem (35%). 3 months after discontinuing corticosteroid treatment, symptoms worsened in 33% of patients.

CONCLUSION

Many patients use corticosteroids uninterruptedly or for long periods of time (47% for more than 3 months) even when they report using them only during disease flares. Many patients are unaware of the long-term effects of the use of corticosteroids, despite the high negative impact on their lives, especially on a personal, social, professional and psychological level. New approaches to the use of treatments would be important to minimize the impact of long-term effects of corticosteroid usage and patient's quality of life.