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BACKGROUND

CONTEXT: People are increasingly using social media (SM) to share information and discuss healthcare matters. It is popular, widespread and a common venue to seek social support and express emotion. Posts generated via SM platforms provide a unique and extensive source for capturing patient insights and perspectives.^{1,2}

OBJECTIVE: The objective of this study was to analyse the trends in utilizing SM for generating patient insights and perspectives in recent years.

METHODS

A systematic literature review was conducted, using PubMed database to identify studies reporting patient insights and perspectives generated using SM listening (SML) methodology within the timeframe between January 2012 and March 2023.

The key words used for the searches were: patient perspective, social media, patient insight, patient experience, and patient view.

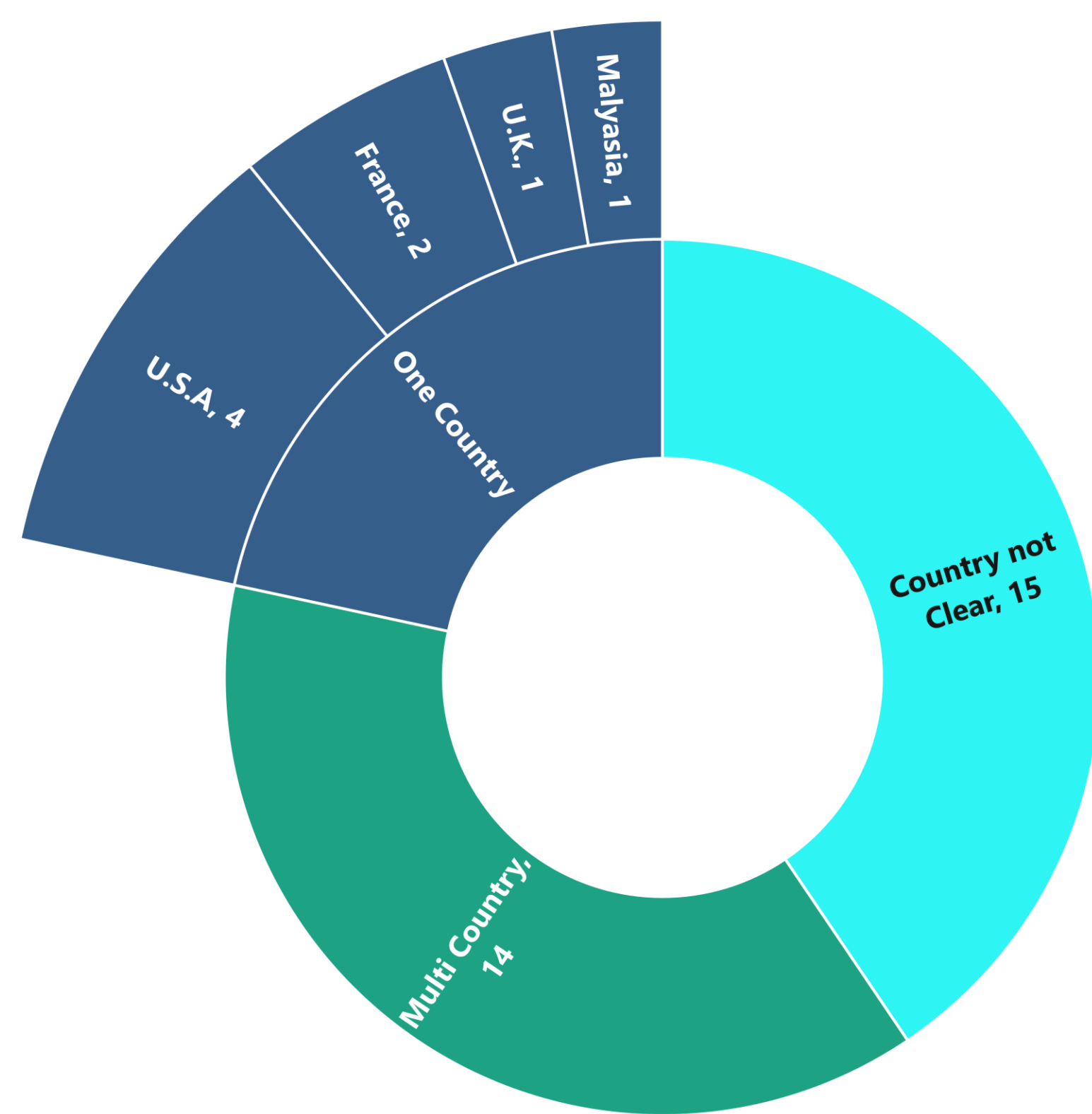
- Only full-text articles published in English were included.
- Information on the country of the post, source of SM post, disease in the study, and the themes that were discussed by patients or their caregivers were extracted.

Data were extracted by one reviewer, and the quality was checked by another reviewer to ensure accuracy. All data were summarised using descriptive statistics.

RESULTS

The search yielded a total of 1,088 articles, of which **37 studies** met the inclusion criteria and were included in the review. Eight studies (22%) analyzed SM posts from one country, fourteen (38%) studies from multi-countries, and fifteen studies (40%) did not clearly report the country of the SM post. (Fig. 1).

Figure 1. Country(ies) of the posts analyzed in included studies (N=37)



43% (n=16) of the studies analyzed posts from **one SM platform**.

57% (n=21) of the studies analyzed posts from **multiple SM platforms**.

In the included studies, **Twitter** (n=21; 57%) emerged as the most used SM platform, followed by **Forums** (n=15; 41%) (Fig. 2).

The number of posts analyzed across studies varied greatly (70 to 355,838 posts). Only a limited number of studies mentioned the sentiment of the posts (n=6). In three of these studies, the proportion of negative sentiments was greater than the positive sentiments.

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References

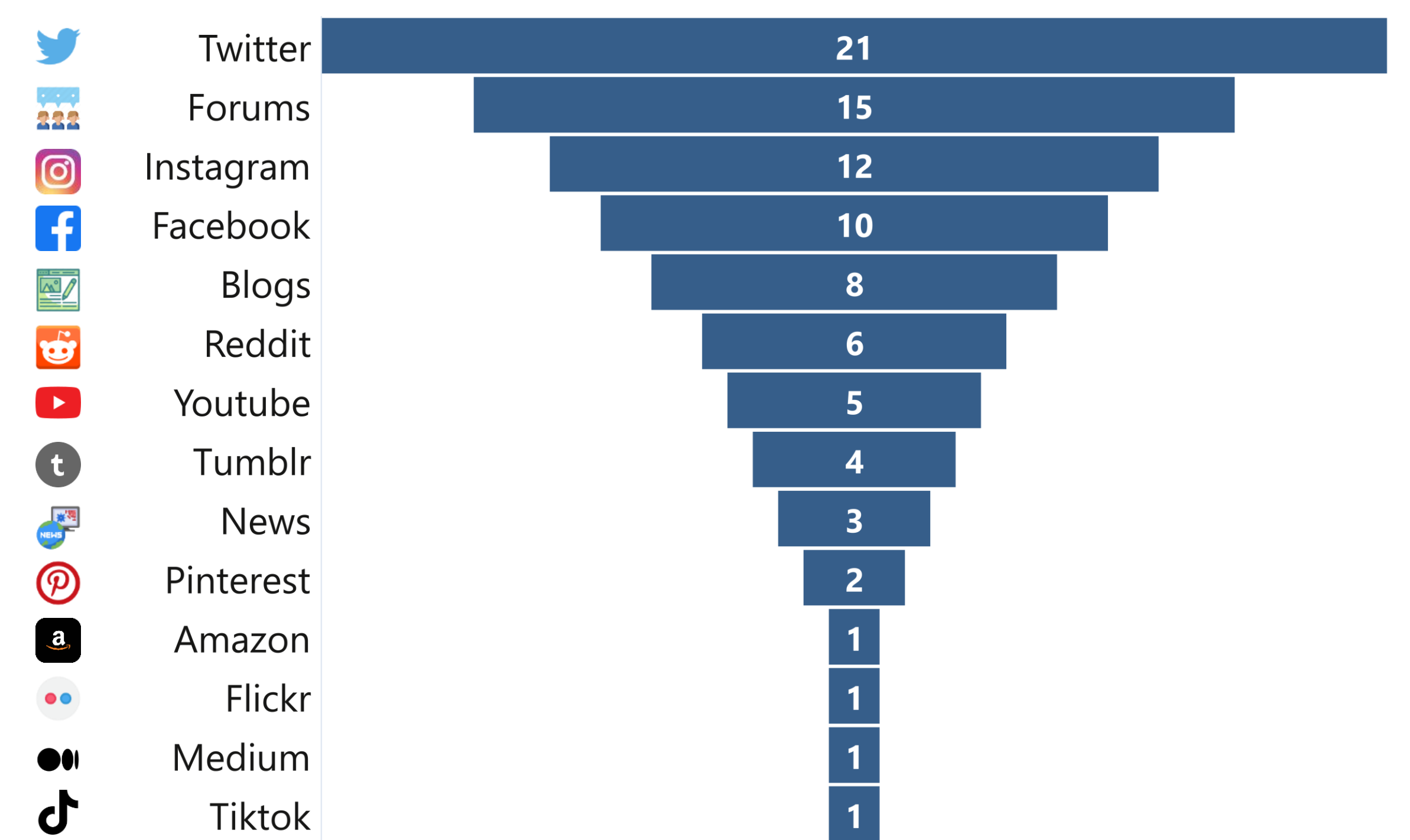
1. Chen J, Wang Y. J Med Internet Res. 2021; 23(5): e17917.
2. McDonald L, et al. BMC Med. 2019; 17: 11.

Twitter is the most frequently used social media platform by patients to express their opinion. Patients mostly discussed **disease symptoms, diagnosis, disease's impact and quality of life**.

SML represents an unexplored opportunity for generating valuable patient insights by exploring untold experiences and outcomes that can complement data collected through traditional methods.

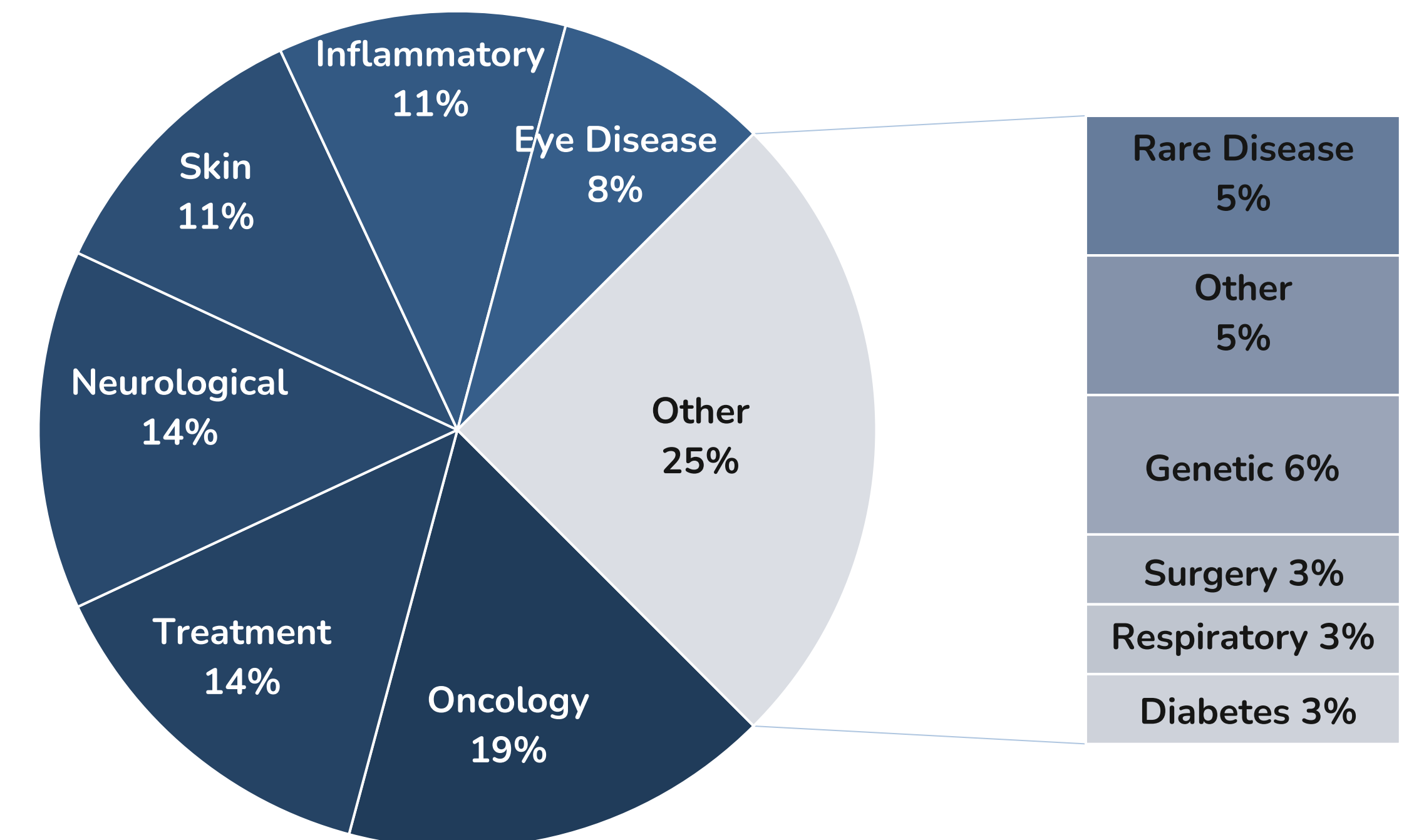
RESULTS cont.

Figure 2. Source of posts across the included studies



The studies comprised of several therapeutic areas, including oncology (19%; n=7), neurological disease (14%; n=5), skin problems, and inflammatory diseases (each 11%; n=4) (Fig. 3).

Figure 3. Disease class in the included studies (N = 37)



On the SM platforms, the most common themes discussed among the patients/caregivers were the disease symptoms (n=16; 43%), diagnosis, physical and psychological impact of the disease, and quality of life (Fig. 4).

Figure 4. Patient discussed themes in the included study



Note : A single study may discuss more than one theme.

