CAN HEALTH FORUMS DEDICATED TO BREAST CANCER BE USEFUL TO CAREGIVERS? Analysis of initial messages on a forum over a one-year period

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Nowadays, internet is the second source of information after doctors. Patient associations developped discussion forums (DF) as a response to help patients living with cancer. Our study **describes the content** of messages posted on a DF dedicated to breast cancer and aims to identify patient needs, especially those linked to supportive care.

METHODOLOGY

This quantitative and prospective study includes all **initial messages** posted on the National Cancer League (Ligue nationale contre le cancer) DF dedicated to breast cancer in 2021.

Esteem support

Tangible support

Administrative questions Clinical symptoms Drug interaction Socio-esthetics Prognosis Alternative medicine

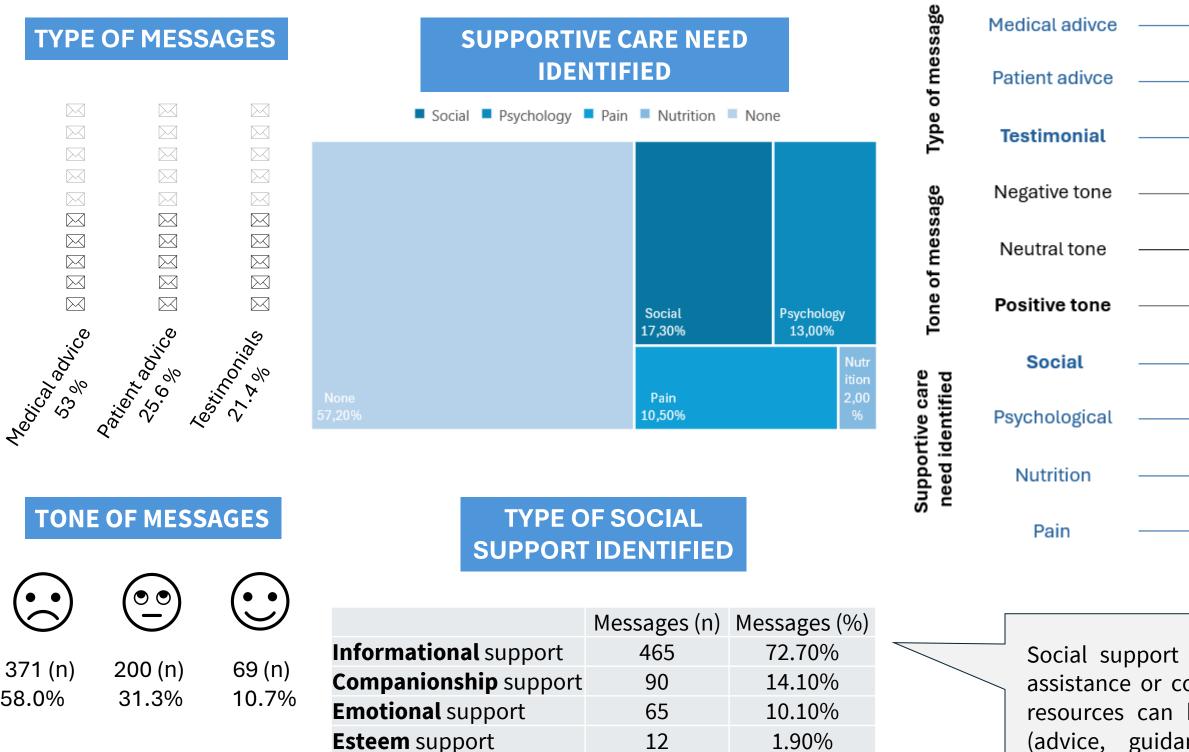
RESULTS



640 initial messages included



312 authors: 275 patients / 37 relatives



8

1.20%

SUBJECTS OF MESSAGES

Forum's life Anxiety after diagnosis Covid-19 Exam's results Adverse events Distrust in caregivers Protocol of treatment Breast reconstruction Anxiety about exam's results Surgical complications Origin of cancer

> NUMBER OF RESPONSES BASED ON MESSAGE CHARACTERISTICS (p < 0,001) 3.55 2.37 3.49 6.54 3.60 2.40 4.80 2.81 2.60

Social support is a psychological concept refeering to the provision of assistance or comfort to others, to help them cope with stressors. These resources can be **emotional** (affection, encouragement), **informational** (advice, guidance), companionship (belonging), tangible (financial assistance, material goods) or **esteem** (promoting one's skills).

LIMITS

REPRESENTATIVENESS

NUMERIC FRACTURE

PERIOD OF THE STUDY

275 patients vs 62000 new cases of breast cancer in France every year

20% of breast cancer affect women aged 75 years above

messages posted during the post-COVID-19 period (less access to supportive care?)

CONCLUSION

NEED OF ADDITIONAL MEDICAL INFORMATION

The first request on the forum was medical advice (53%) even after a medical **consultation** because over 50% of the messages mentioned previous medical advice from a doctor. Relatives also need additional medical information as they published only 2,9% of testimonials vs 12,4% of medical advice (p<0.001). The most frequent subject was adverse events of a non-surgical treatment (18.4% of messages).

CRUCIAL PERIODS IN PATIENT PATHWAY

Two periods are identified as crucial: the **diagnosis waiting time** and the **follow-up**. During the diagnosis waiting time, 71.9% of messages requested medical advice vs 53% of all messages (p<0.001). In the same way, during the follow-up, 60.3% of messages requested medical advice (p=0.003). During the diagnosis waiting time, the most identified supportive care need was psychological support.

NEED TO MEET UP WITH PATIENTS

Our results suggest that patients wish to **create a community** on the forum, sharing difficulties and hopes. Companionship was the first social support identified on the forum. Testimonies elicited more responses than medical or patient advice requests (p<0.001) and companioship messages elicited more responses than other types of social support.





