

# A DEVELOPING ASPECT OF HEMOPHILIA NURSING: THE ROLE NURSES PLAY IN CLINICAL TRIALS



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**INTRODUCTION:** Clinical trials which has been increasingly developing in recent years has intensified its activities in hemophilia disease as in many other diseases. Hemophilia clinical trials aiming that hemophilia patients should receive more effective and long-term "factor" treatment also promises hope for hemophilia patients. Hemophilia clinical trials research is held in hemophilia treatment centers well equipped for the treatment and care of hemophilia patients with an understanding of the multidisciplinary team. One of the members of hemophilia research team is hemophilia nurses. A clinical research nurse's roles range from patient selection to ensuring patient compliance to the treatment, diagnosing deviations from normal course of the disease as early as possible and coordinating the team. The clinical research being performed in Turkey since 1995 are being conducted at 8 sites with their principal responsible investigators and their own staff. It is requested that study nurse to be involved in the clinical trials as an active role player. The question is what the idea of the the nurses involved in hemophilia care is and whether they have enough enthusiasm with the clinical trials.

**AIM:** The aim of the study is to identify the nurses' who involved in hemophilia care opinions about clinic trials. In this research, it had been interviewed face to face with 40 nurses who have been involved in hemophilia care. Three of them have been excluded since they could not be completed due to different reasons. The data were collected with descriptive and semi-structured open comment questions. Totally 37 interviews were evaluated and analyses statistically.

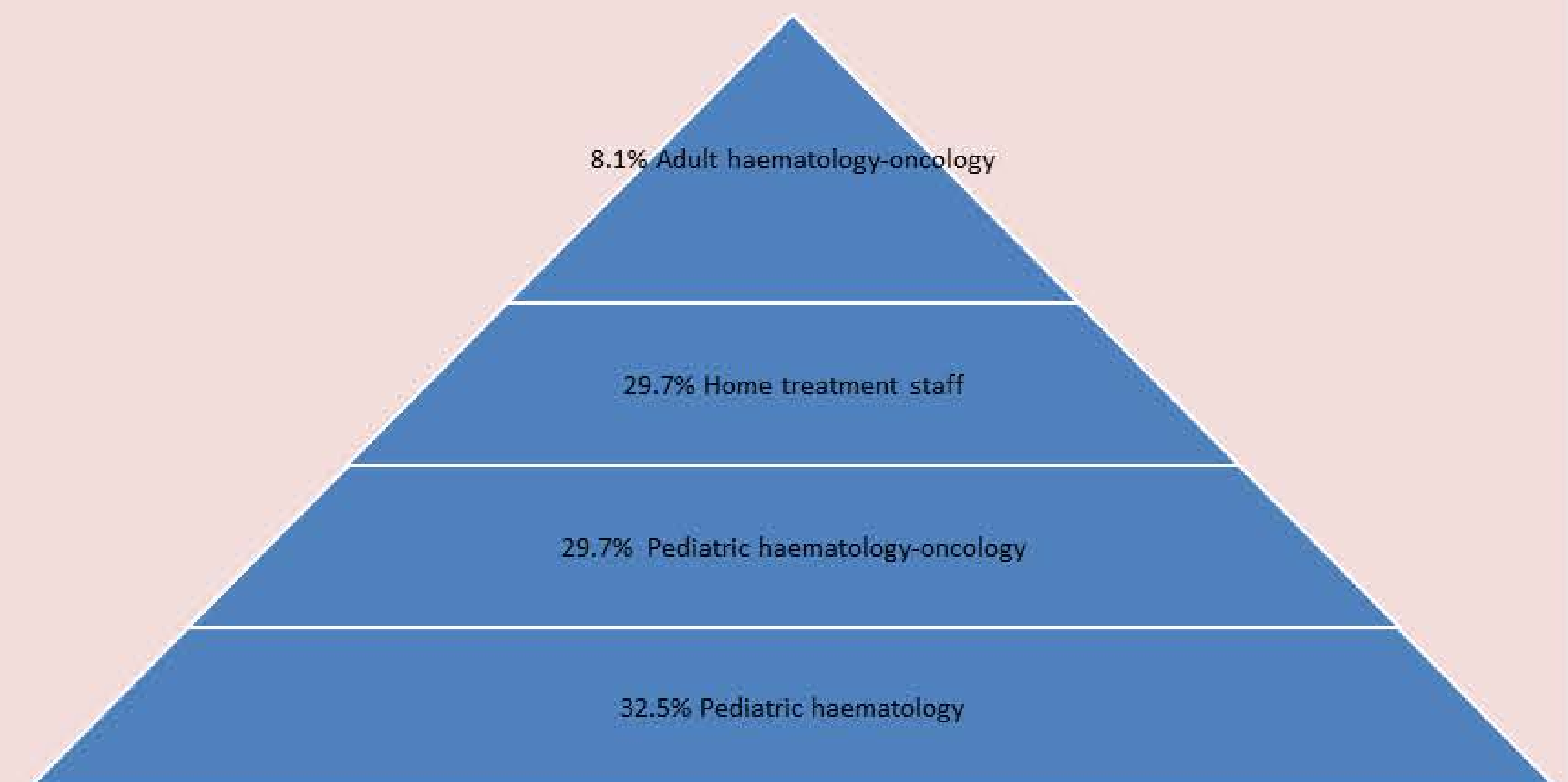
While of the nurses, 76.6% were interested in clinical trials conducted for the treatment of hemophilia and thus wanted to take part in trials, 13.5% thought that the nurse had no role in hemophilia clinical research and thus were not interested in this issue. Similarly, 13.5% of them indicated that clinical trials concern only physicians and pharmacologists. Of the nurses, 40.5% were trained about the clinical studies of hemophilia and **10.8%** were the members of a clinical research team.

## The opinions the study nurse (10.8%) in clinical trials

- Coordinate the communication in the trial staff
- Play an active role in selecting the eligible patients
- Inform the parents of the patients
- Direct to the physicians and provide them psychological support
- Administration of the trial product and recording

**RESULTS:** In this study, 37 nurses who participated in the treatment of hemophilia were asked to give their opinions about their roles in clinical trials. The average age of the participants is 37,7 and the average of their experience as hemophilia nurse is 15,1(min.2-max.37). The experience average at their own department is 6,5 (min.1-max.24).

## Nurses' Clinic Departments



Since the nurses working at pediatric and adult haematology-oncology care with both haematology and oncology patients(37.8%), they stated that the patient number is too high and they have not got enough energy for the study nurse role in the clinical trials.

**CONCLUSION:** Formerly, being a member of a clinical research team was considered as «extra-workload»; however, at present, there is an increasing interest in and demand for this role due to increases in clinical research team's experiences and positive developments in the issue.

\* NO CONFLICT OF INTEREST

