

PROBE Nicaragua

Quality of life of people with hemophilia in Nicaragua: A case series with PROBE Survey

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INTRODUCTION

Hemophilia is a disorder caused by the deficiency of coagulation factor VIII or IX. Hemorrhage is the characteristic sign that mainly affects muscles and joints, causing chronic pain and functional disability, conditions that decrease the quality of life (QoL).

AIM

The purpose of this study was to evaluate the QoL of people with hemophilia who live in Managua, Nicaragua.

METHOD

Descriptive study of a series of cases. 40 patients with hemophilia older than 19 years old were selected to participate. From June to September 2020 was applied the PROBE survey (Patient Reported Outcomes, Burdens and Experiences) from McMaster University endorsed by the World Federation of Hemophilia and Asociación Nicaragüense de Hemofilia.

CONCLUSIONS

The study population reports a decrease in their QoL, with difficulties in performing activities due to persistent joint pain, which limits their ability to interact in the social environment. The mental sphere was also affected with feelings of anxiety and depression. Therefore, it is necessary to guarantee multidisciplinary care with emphasis on improving drug treatment, rehabilitation and mental health.

ACKNOWLEDGEMENT

It is important for the Nicaraguan Hemophilia Association to develop training and spread information about this disease with the People with Hemophilia and relatives. Is important to strenght the investigations about hemophilia focused on health attention and by this way guarantee the QoL. We recommend to the universities to promote the investigations on Hemophilia. The Health professionals required to provide a multidisciplinary attention focused on rehabilitation, pain therapy and mental health.

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RESULTS

The mean age was 31.48 years (SD \pm 8.13), 100% of the participants were men, 80% had hemophilia A and 20% hemophilia B. Their severity was mild 32.5%, moderate 27.5%, severe 30%, indeterminate 10%. 87.5% referred to chronic pain associated with climbing stairs and walking. 55% were overweight. 30% had 2-3 hemorrhages in the last year, with the left knee being the most affected joint. 29.5% use a cane, all take painkillers. 38.5% receive factor VIII / IX as concentrated treatment and 36.3% fresh frozen plasma. 52.5% reported difficulty in bathing and dressing, 70% expressed mild / moderate problems performing usual activities and 50% reported mild pain / discomfort. In the mental sphere, they expressed feeling mild or moderately anxious / depressed due to their health condition.

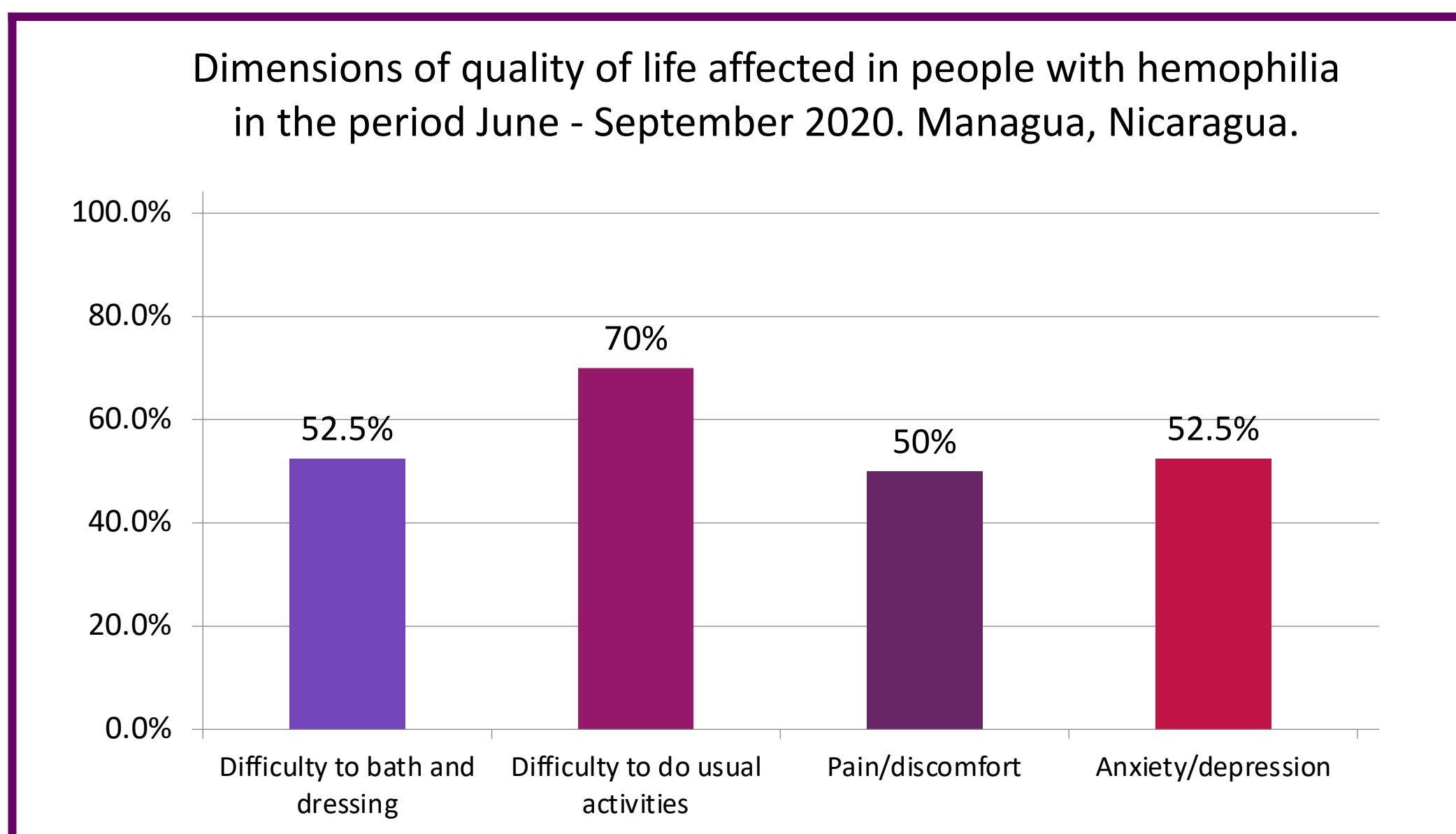


Figure 1: Dimensions of quality of life affected in people with hemophilia in the period June - September 2020. Managua, Nicaragua.

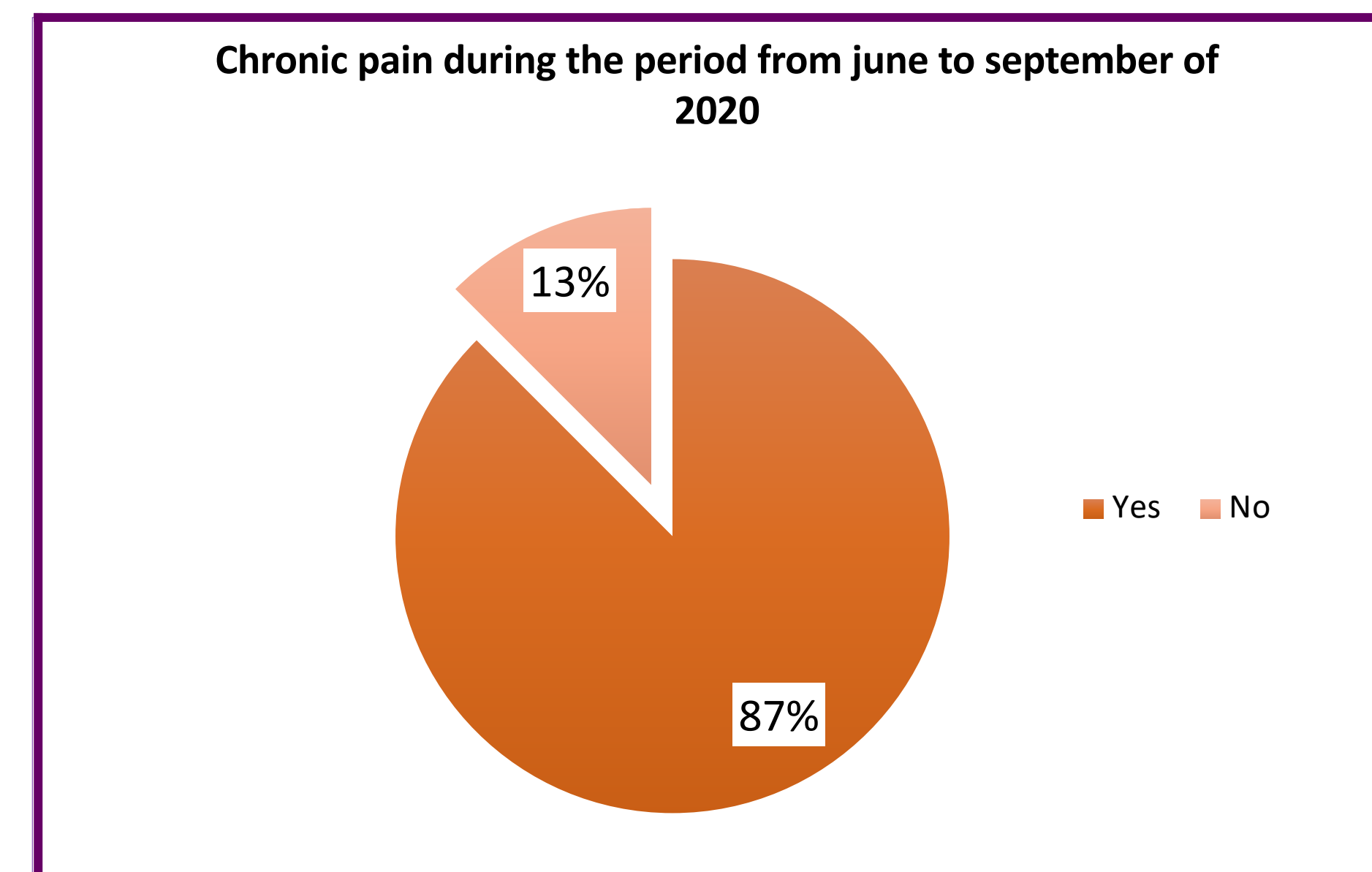


Figure 2: Chronic pain during the period from June to September of 2020. Managua, Nicaragua

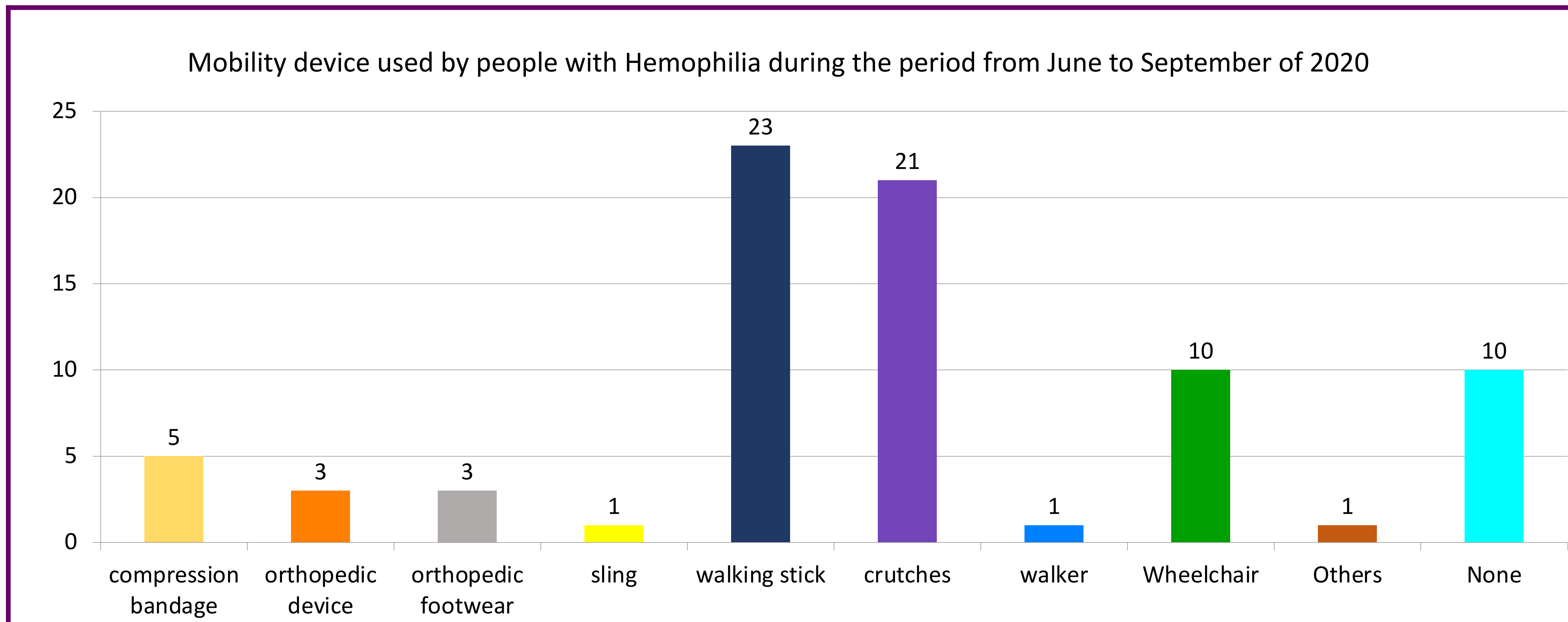


Figure 3: Mobility device used by people with Hemophilia during the period from June to September of 2020

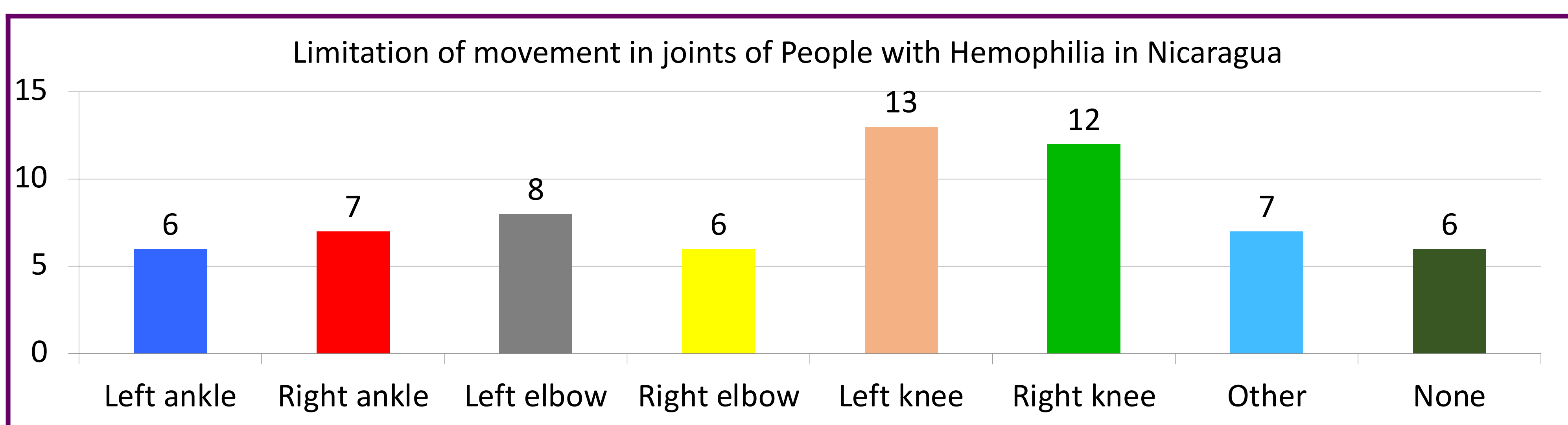


Figure 4: Limitation of movement in joints of People with Hemophilia in Nicaragua in the period from June to September 2020.

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