

Foreword

By incidence, or the proportion of people suffering from a disease in the general population, haemophilia belongs into the group of rare diseases. As a rule, our knowledge about such diseases is limited, causing problems primarily to the patients and their families, their immediate and wider community, and finally doctors and the health system as a whole. Fortunately, the general insight into the specificities of haemophilia has begun to increase in recent times, and this book aims to make a contribution to this trend. Our goal is to raise the level of knowledge about the specificities of the disease, and the characteristics of the quality of life of persons with haemophilia presented from their own perspective.

The book is thematically divided into two parts. In the first, introductory part, medical aspects of haemophilia are described: the history, epidemiology, pathophysiology, typology, clinical picture, diagnostics and therapeutic options.

The second part provides a detailed portrait of the lives of adults with haemophilia in Croatia. The data on which it is based were collected as part of the project HEMOQoL – *Quality of Life of Adults with Haemophilia in Croatia – Medical and Psycho-social Aspects*, which was carried out by means of a survey among members of the Croatian Haemophilia Society. As can be anticipated from the Project title, the study included objective and subjective indicators of the quality of life, i.e. the sociodemographic, health-related and (socio)psychological status of patients.

In order to gain insight into sociodemographic and economic status, respondents were asked to answer questions about their age, education, residential status and territorial dispersion, marriage and parental status, household and housing characteristics, as well as work and material status (living standard).

Health status was assessed by a battery of questions, consisting of several broader categories. These included the basic data on haemophilia, current treatment and attitude towards treatment, details on bleeding, pain, damage and comorbidities, mobility and anthropometric features, dental status, dietary habits (including the use of dietary supplements and narcotics), and coping with the disease.

Like the health status, the daily functioning and (socio)psychological status were checked in detail as well. The thematic units in this part of the survey were

social functioning and support, religiosity, leisure time and restrictions of everyday activities, sexuality, personal well-being and life satisfaction, the psycho-social aspects of haemophilia and psychological well-being, media use, and attitudes and orientations regarding the social issues potentially relevant for the lives of the patients. Furthermore, the impact of the stressful context in which the study was conducted, marked by the coronavirus pandemic and earthquakes, was also taken into account.

The authors thank all who contributed in any way to the creation of this book, especially the members of the Croatian Haemophilia Society, who responded to the survey. The Croatian Haemophilia Society not only initiated this project, but provided financial, logistic and other preconditions for conducting the research.

The authors thank the Institute of Social Sciences Ivo Pilar for ensuring that the study is carried out according to the highest scientific standards. The Institute is an internationally recognized scientific institution with a longstanding tradition of conducting empirical research in various fields. Research into the quality of life is at the very core of its activity. Therefore, the implementation of this project by the Pilar Institute can be seen as a continuation of its longstanding research tradition, and at the same time as a guarantee of the quality of the final product.

In addition, the authors thank the Croatian Academy of Sciences and Arts and its Department of Medical Sciences for active involvement in the publication of this book and dissemination of knowledge on this rare disease.

Finally, the Croatian Haemophilia Society would like to thank all the business entities with which it cooperates and which have enabled through their engagement, donations and sponsorships the realization of this research project and the publication of this book – Agmar, Bayer, BioMarin, Novo Nordisk, Octapharma, Pfizer, Roche, Sobi and Takeda.

We hope that this book will contribute to the upgrading of knowledge about the specificities of living with haemophilia, and that it will prove beneficial to patients in Croatia, as well as to patients worldwide.