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Mobile Health Technology for the Personalized Therapy of Hemophilia

Noemi Dirzu[1†], Ionut Hotea[1,2,3†], Ciprian Jitaru[2,3], Melen Brinza[4,5], Laura Urian[2,3], Mareike-Catrina Peters[1], Krisztina Gal[1], Louis Popescu[1], Cristina Blag[6,7], Mirela Marian[1], Eva Pal[1], Marilena Stanescu[8], Diana Cenariu[1], Cristina Tarniceriu[9,10], Margit Serban[11,12], Delia Dima[3], Daniel Coriu[4,5] and Ciprian Tomuleasa[1,2,3]*

[1] *Medfuture Research Center for Advanced Medicine, Iuliu Hatieganu University of Medicine and Pharmacy Cluj Napoca, Cluj Napoca, Romania,* [2] *Department of Hematology, Iuliu Hatieganu University of Medicine and Pharmacy Cluj Napoca, Cluj Napoca, Romania,* [3] *Department of Hematology, Ion Chiricuta Clinical Cancer Center, Cluj Napoca, Romania,* [4] *Department of Hematology, Fundeni Clinical Institute, Bucharest, Romania,* [5] *Department of Hematology, Carol Davila University of Medicine and Pharmacy Bucharest, Bucharest, Romania,* [6] *Department of Pediatrics, Iuliu Hatieganu University of Medicine and Pharmacy Cluj Napoca, Cluj Napoca, Romania,* [7] *Department of Hematology, Emergency Clinical Children's Hospital, Cluj Napoca, Romania,* [8] *Takeda Pharmaceutical Company, Tokyo, Japan,* [9] *Department of Anatomy, Grigore T. Popa University of Medicine and Pharmacy, Iasi, Romania,* [10] *Department of Hematology, St. Spiridon County Clinical Emergency Hospital, Iasi, Romania,* [11] *Department of Hematology, Victor Babes University of Medicine and Pharmacy Timisoara, Timisoara, Romania,* [12] *European Haemophilia Treatment Center, Timisoara, Romania*

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**Correspondence:*
Noemi Dirzu
noemidirzu@gmail.com

†*These authors have contributed equally to this work and share first authorship*

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The management of patients with hemophilia has evolved significantly since the first treatment attempts were made in the late 1930s. Since then, each new step in the treatment of patients with hemophilia has brought important advancements, as well as its unique set of challenges. Today, a patient-centered, individualized comprehensive approach is the new paradigm, moving away from the traditional "one size-fits-all" approach, to provide the best possible care for each patient with a bleeding disorder. As part of this complex task, mobile health applications might have the capacity to play an important role in reaching that goal. However, the use of new electronic technologies as part of a comprehensive treatment approach for patients with hemophilia simultaneously presents a new set of challenges that needs consideration. In the first section, currently available treatment of hemophilia patients will be revised, while in the second part the role of IT software in the treatment monitoring of hemophilia patients will be discussed.

Keywords: hemophilia, IT technology, patient-tailored monitoring, mHealth, application monitoring

INTRODUCTION

Hemophilia is a group of rare bleeding disorders, recessive genetic diseases linked to the X chromosome (1, 2). Due to the lack of coagulation factors from the intrinsic pathway, patients present with prolonged bleeding after injury, easy bruising, or even spontaneous bleeding (3). These symptoms pose a great risk of permanent damage if the bleeding occurs internally, inside the joints, intramuscularly, or intracranially (4). Diagnosis is made usually in early childhood, when the first bleeding episodes occur. There are two main types of hemophilia: A (HA), caused by the deficiency of factor VIII (FVIII) and B (HB) caused by the deficiency of the Christmas factor (FIX). Acquired hemophilia appears later in life, due to the formation of antibodies against the coagulation factors (5). Even more rare are the cases of hemophilia C, due to the lack of factor XI (6), and parahemophilia, caused by the lack of factor V (7). Depending on the plasma levels, hemophilia can be mild (plasma clotting factor levels of 0.05–0.4 international units (IU)/mL),