

Introduction to the New Version of PWS Application and Its Use in Medical Practice

Jinsup Kim, Aram Yang, Sung Yoon Cho, Dong-Kyu Jin

Department of Pediatrics, Samsung Medical Center, Sungkyunkwan University School of Medicine, Seoul, Korea

Today's mobile phones and tablet PCs offer a considerably wider range of functionalities than before. Mobile applications (apps) are increasingly used for managing various daily health tasks. Currently, more than 165,000 health-related apps are offered on all the stores of different platforms. Pf Jin and the Association for Research on MPS and Rare Diseases (AMARD) have helped Prader-Willi syndrome (PWS) families through medical information and family support since 2015. AMARD developed the first mobile application for Korean patients with PWS, which was released to a limited number of patients under the age of 3 and only provided to Android users. The first version of the PWS application focused on growth hormone therapy and the assessment of growth and development by parents in infant and early-childhood PWS patients. The 2016 version of the PWS application has been improved in many different ways. We have expanded the subjects of the application to late childhood and adolescent groups, changed the user interface accordingly, and made the application available for iOS users. We will show the specialized growth curves of older children with PWS. Therefore, patients with PWS over the age of 3 and their parents can assess the patients' growth. Additionally, we have upgraded the growth hormone therapy menu by improving the input system for the growth hormone therapy injection schedule and the daily growth profile (height and weight). We expect that the new version of the PWS application will help many PWS families cope with growth hormone therapy and evaluate the effects of growth hormones in better ways. Additionally, we are making a constant effort to provide more useful information about patients with PWS in many aspects.

Keywords: Prader-Willi syndrome, Mobile application, Growth hormone therapy

Today's mobile phones and tablet PCs offer a considerably wider range of functionalities than before. Mobile applications (apps) are increasingly used in managing various daily health tasks. According to a recent report by the IMS Institute for Healthcare Informatics, more than 165,000 health-related apps are offered on all the stores of different platforms^{1,2)}. In fact, health apps, which have a share of about 3 percent of all active apps in Apple app stores³⁾, have become the third-fastest growing category after games and utilities²⁾.

According to reports, one third of health apps were designed for more specific areas, such as professionals or people affected by a specific disease^{1,2)}. However, more than 50% of the available apps received less than 500 downloads, and the IMS Institute for Healthcare Informatics attribute this situation to the poor quality of many of them, the lack of guidance on the usefulness of apps,

and a low level of support from health professionals^{1,2)}.

Prader-Willi syndrome (PWS) is characterized by neonatal hypotonia, poor sucking in infancy, early-onset hyperphagia, and the development of morbid obesity in children, and GH therapy is essential for improving muscle strength and physical function, normalizing height, increasing lean body mass and mobility, and decreasing fat mass⁴⁾. Therefore, a method for establishing appropriate and steady PWS-specified GH treatment should be provided by a PWS specialist.

Pf Jin and the Association for Research on MPS and Rare Diseases (AMARD) have helped PWS families through medical information and family support since 2015. AMARD developed the first application for Korean patients with PWS, which was released to a limited number of patients under the age of 3 and only provided to Android users. The application is a valuable supple-

Received December 19, 2016; Revised December 21, 2016; Accepted December 28, 2016

Correspondence to: Dong-Kyu Jin

Department of Pediatrics, Samsung Medical Center, Sungkyunkwan University School of Medicine, 81 Irwon-ro, Gangnam-gu, Seoul 06351, Korea
Tel: +82-2-3410-3525, Fax: +82-2-3410-0043, E-mail: jindk@skku.edu

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ment to many services that AMARD provide. The professional PWS specialists at AMARD try to provide high-quality, useful information continuously through this application.

The first version of the PWS application focused on growth hormone (GH) therapy and the assessment of growth and development by parents in infant and early-childhood PWS patients. It features a cute character for infant users with PWS. With the PWS app, parents who have children with PWS can monitor the effectiveness of GH therapy for their children and obtain the exact dose and therapy schedule information. Additionally, the distinct growth and development of children with PWS can be checked through the simple reports of their parents and be compared with known milestones of PWS. In addition to basic information on GH therapy and the evaluation of the growth and development of PWS patients, the former version of the PWS app provided easy-to-understand medical information about PWS.

The 2016 version of the PWS application has been improved in many different ways. We have expanded the subjects of application to late childhood and adolescent groups and changed the user interface accordingly. Furthermore, this application now extends to iPhone users through the Apple app store on iOS. We show the specialized growth curves of older children with PWS in addition to the growth curves of infants with PWS that were provided in the former version. Therefore, patients with PWS over the age of 3 and their parents can assess the patients' growth. Additionally, we have upgraded the growth hormone therapy menu by improving the input system for the hormone therapy injection schedule and the daily growth profile (height and weight).

We expect that the new version of the PWS application will help many PWS families cope with growth hormone therapy and evaluate the effects of growth hormone in better ways. Medical information that can help improve the everyday lives of children with PWS and their parents will be provided in the next version. Furthermore, we are making a constant effort to provide more useful information about patients with PWS in many aspects.

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