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Designing a smartphone application to support family caregivers of children with acute lymphoblastic leukemia

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Background: Acute lymphoblastic leukemia (ALL) is the highest incidence malignancy among children under the age of 15 years old. For the limited cognitive ability of the children with ALL, family caregivers especially for the children's parents are essential partners in the delivery of complex health care services and are mainly responsible for taking care of children in and out of the hospital. Thus, caregivers have huge care burden and urgently need professional and available support which can be satisfied by the technique of mobile health.

Objective: To document the process of designing an application (app) operated on Android smartphones based on Internet, which is designed specifically for family caregivers of children with ALL.

Methods: Mixed methods encompassing individual interviews and group discussions with the stakeholders including ALL children's family caregivers, professors in cancer care, and software engineers were used in this formative research.

Results: The varied stakeholders welcomed the idea of developing a smartphone app to support the family caregivers of children with ALL. Our formative research revealed several major demands of the caregivers in taking care of the children with ALL: limited access to evidence-based information, lack of social support and communication with doctors or nurses, insufficient disease-related knowledge, and inconvenient of recording the treatments and medical results. The feedback was incorporated into the development of the smartphone app. And finally we developed an app operated on Android smartphone with eight major modules: personal information, treatment tracking, family care, social support, knowledge education, self-assessment questionnaires, interactive platform and reminding module. And we also have a web-based backstage help to ensure the management of the basic function of the app.

Conclusions: The mixed-method formative research led to the design of the smartphone app to support the family caregivers of children with ALL. The involvement of stakeholders were critical in the planning and design of the app in order to enhance program relevance, appeal, and match with the needs of target users.

Biography

Changrong Yuan has completed her PhD at the age of 36 years from Shanghai Second Military Medical University, China. She is the Professor of Nursing School of Shanghai Second Military Medical University. She has published more than 120 papers in reputed journals and serving as an editorial board member of 6 SCI journals. In addition, Dr. Yuan is the editor-in-chief for Nursing Journal of Chinese PLA, a Chinese leading nursing journal since 1993. She serves as an advisory panel member for many kinds of grants review.

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