Understanding Digital Information Needs of Supportive Care for Chinese Children with Cancer and Their Families: The Perspectives of Multi-Stakeholders

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1. Introduction

Children with cancer and their families endure multiple challenges during treatment and also in survivorship. Digital health technologies provide an innovative way to support their needs. However, there remains gap about the digital information needs of supportive care for Chinese children with cancer and their families, especially from the perspectives of multi-stakeholders. This study aimed to understand the digital information needs by interviewing pediatric cancer patients, their families, nurses and physicians, which provide the foundation for developing a digital platform.

The project has been approved by the ethics committee of Shanghai Medical College of Fudan University (IRB#2019-02-06) and the ethics committee of School of Nursing, Fudan University, Shanghai, China. This study was supported by Fudan University-Shanghai Medical College-Qingfeng Project, China National Natural Science Foundation of China Youth Science Foundation (71904030), Shanghai Pujiang Talent Program (2019PJC006).

2. Approach

Semi-structured interviews were conducted with a purposive sample of multiple stakeholders (children, families, nurses and physicians) in the Hematology and Oncology department of Children’s Hospital of Fudan University, Shanghai, China in January, 2021. Questions in interviews guide included: understanding of their disease (for children and parents); the digital information they currently got (for children and parents) or being provided (for nurses and physicians) during previous treatment experience; perceptions and comments about the current digital information provided;

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digital information needs that were met during each treatment stage; suggestions for
developing a digital platform to support Chinese children with cancer and their families.
All the interviews were recorded and transcribed verbatim. We used a qualitative content
analysis where themes and categories are obtained from the data on the context of the
pre-determined questions. Transcripts were independently reviewed and coded by all
three authors and an additional research assistant. After coding, we worked together to
find consensus on the themes.

3. Body

A total of 6 patients, 12 parents, and 1 physician and 5 nurses were recruited. The subjects
of the study included 6 children aged 7 to 10, mainly diagnosed with acute leukemia for
an average of 1 year. Five nurses aged 27-38 with mainly worded for hematology
oncology for an average of 7.6 years. A physician with doctor degree has worded for two
years. Of the 13 parents, three of them are fathers, and the remaining ten are mothers,
with different degree from junior high school to bachelor degree.

Three themes and ten subthemes emerged from the data. Theme 1 “the main contents
digital information needs”: Subtheme 1 disease and treatment information; Subtheme
2 caring information; Subtheme 3 mental health information; Subtheme 4 finical support
information. Theme 2 “the way of meeting digital information needs”: Subtheme 5
accompanying cancer trajectory; Subtheme 6 in and outside of the hospital. Theme 3
“factors influencing digital information needs”: Subtheme 7 disease factors; Subtheme 8
family factors; Subtheme 9 digital planforms; Subtheme 10 community factors.

4. Conclusions

This study shows that the information needs of children with hematological tumors and
their parents in participating in family supportive care for children have not been fully
satisfied. There is an urgent need for us to take the needs of children and their parents
as a starting point and carry out a targeted digital platform to support them.

According to different stages of illness and different care situations inside and
outside the hospital, comprehensively provide information including medication,
treatment, in-hospital and home care of the child, and provide interesting and easy-to-
understand targeted information to the child and the parent of the child in different tones.
We will conduct a more in-depth study on this in the next stage.

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