

Abstract

Background: While the life expectancy of childhood cancer has improved dramatically, late complications after the disease are issues of growing concern. Late complications include organ dysfunction, infertility, growth dysfunction, neurocognitive dysfunction etc. In particular, neurocognitive dysfunction has a profound impact on the life of childhood cancer survivors (CCS) in later years, and necessary interventions are desired. However, in Japan, there are only objective indicators and no scale to measure subjective difficulties. The Childhood Cancer Survivor Study-Neurocognitive Questionnaire (CCSS-NCQ) developed by St. Jude Children's Research Hospital in the United States is a self-administered scale for screening daily difficulties regarding the organization, emotional regulation, memory, and task efficiency, and is utilized in clinical practice in the United States. In this study, we developed the "CCSS-NCQ Japanese Version" and evaluated its reliability and validity. **Method:** All cancer types were included, and childhood cancer survivors aged 10 years and older were asked to complete a 33-question self-administered questionnaire. We distributed paper-based questionnaires directly in person to the first 90 participants, and then changed to an online survey using Google Forms due to the difficulty of direct contact with CCS during the COVID-19 pandemic. In total, responses from 123 participants were collected. During the process, we conducted linguistic validation and refined the readability and clarity of the questionnaire together with the patient associations. **Results:** The mean age of participants was 21.7 ± 8.5 years old; 50.4% of them were male. The mean age at diagnosis was 8.5 ± 4.8 years old, and 42.3% of them were diagnosed with brain tumor, 34.1% with hematological malignancy, and 13.0% with

solid tumor. Exploratory and confirmatory factor analysis was conducted using the collected data. A principal component analysis using Promax rotation, with the setting of the factor loading 0.4 showed a four-factor structure similar to the original CCSS-NCQ. The CCSS-NCQ Japanese version obtained Cronbach's alpha of 0.842 - 0.918.

Conclusion: The reliability and the validity of the CCSS-NCQ Japanese version were established in this study. This is the first Japanese self-administered screening measure of neurocognitive dysfunction that is compatible internationally, and it is hoped that it will be applied clinically. The use of the scale is expected to facilitate detection of neurocognitive dysfunction affecting the daily lives of CCS. This standardized, validated, self-reported measure is expected to lead to referral of CCS with positive screening for formal neurocognitive assessment and the establishment of a system to provide appropriate evidence-based education support. We will continue to enroll participants to improve the robustness of the scale.

Keywords: CCSS-NCQ Japanese version, Childhood Cancer Survivors, Neurocognitive dysfunction, task efficiency, emotional regulation, organization, memory