

Reported Effects of the sars-cov2 Pandemic on the Activities of People with Cerebral Palsy in Portugal

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Background and Objectives

People with chronic conditions affecting their health and their ability to be autonomous and socially included, are particularly sensitive to sudden, severe disturbances of the social environment, especially if affecting also their formal and informal caregivers, as well as the infrastructures that support them. The voices of these individuals are seldom heard, their needs often unattended. People living with cerebral palsy (CP) are paradigmatic of the potentially difficult situation presented by the SARS-CoV2 pandemic.

Study Design

Project "Barómetro COVID-19 e Paralisia Cerebral" monitors how the SARS-CoV2 pandemic affects people living with CP, hearing their own voices, through a web-based, self-applied, anonymous, mixed-responses survey of people having CP, their relatives, caregivers and cohabitants, technicians and associative officials that support them. It has a common core of questions with "Barómetro COVID-19: Opinião Social" (NOVA National School of Public Health). Being a dynamic tool, questions can be added, as indicated by the periodical, intermediate analyses.

Study Participants & Setting

People living with CP were invited to participate by the Federation of Portuguese Associations for Cerebral Palsy and the Portuguese Surveillance of Cerebral Palsy. The survey is available and ongoing from April 6th 2020. Data from responders self-identified as having cerebral palsy and data related to them, reported by relatives, cohabitants, caregivers and technicians, were considered for this analysis. Data reported until December 26th 2020 were considered. The period includes different legal settings and restrictions to movement and social activity, it ends with the beginning of vaccination against Covid-19 in the European Union.

Materials/Methods

Descriptive, non-parametric statistics were applied.

Results

Data on the daily life of people having CP were retrieved from 1102 surveys, 168 filled by individuals with CP and 289 by relatives, caregivers and cohabitants of individuals with CP.

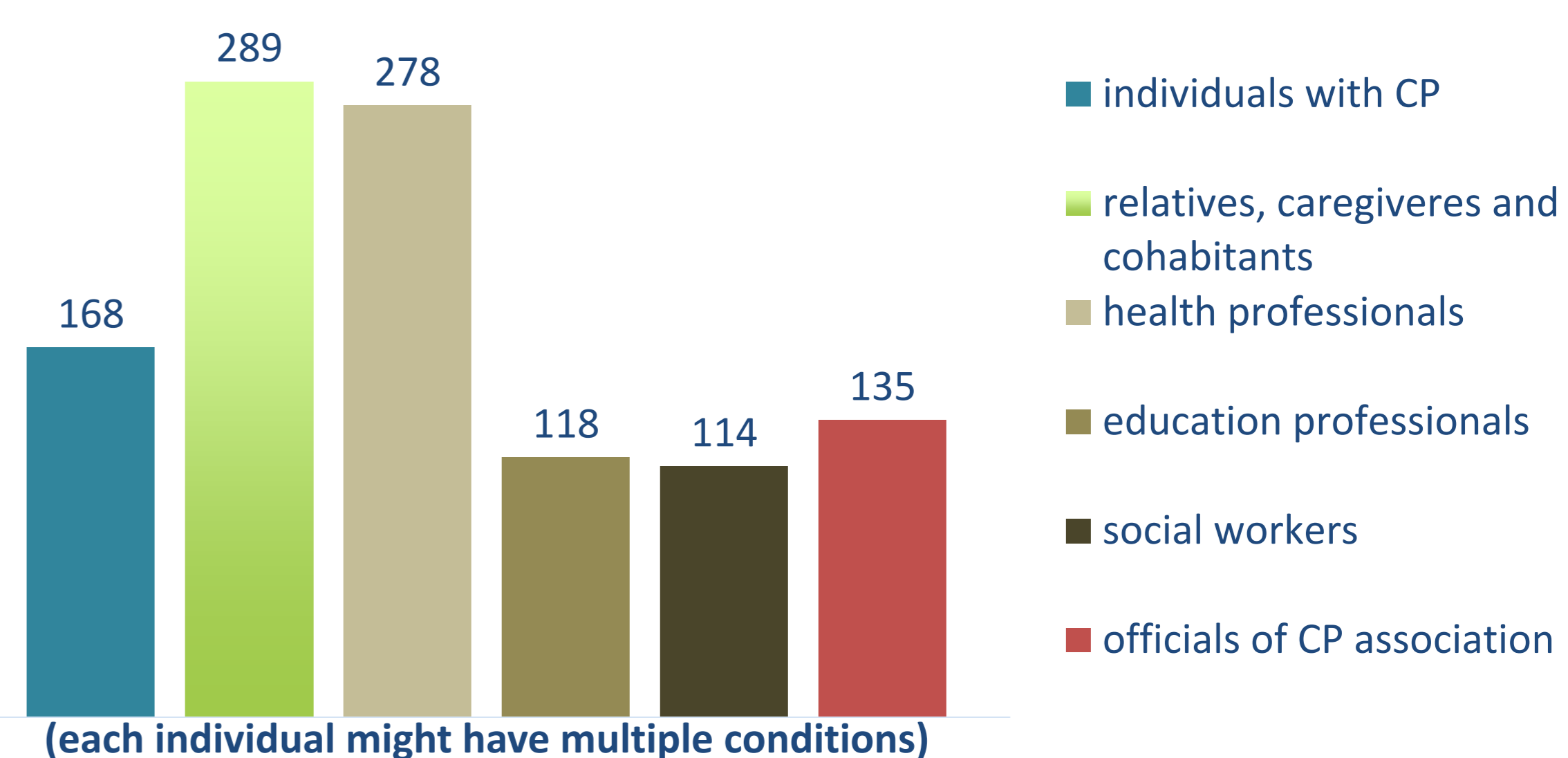
Most of the respondents (96%) reported substantial changes in daily routines: school, day-center, activity centre were suspended (62%), working conditions changed (22%), and 24% had been quarantined or kept on social isolation; 87% of individuals with CP avoided being out from home (59% never left their homes for at least 2 weeks).

Many people having CP had face-to-face rehabilitation and health care sessions cancelled (43%) or choose to cancel them (23%); had home-based basic healthcare services cancelled (21%) or choose to cancel them (15%).

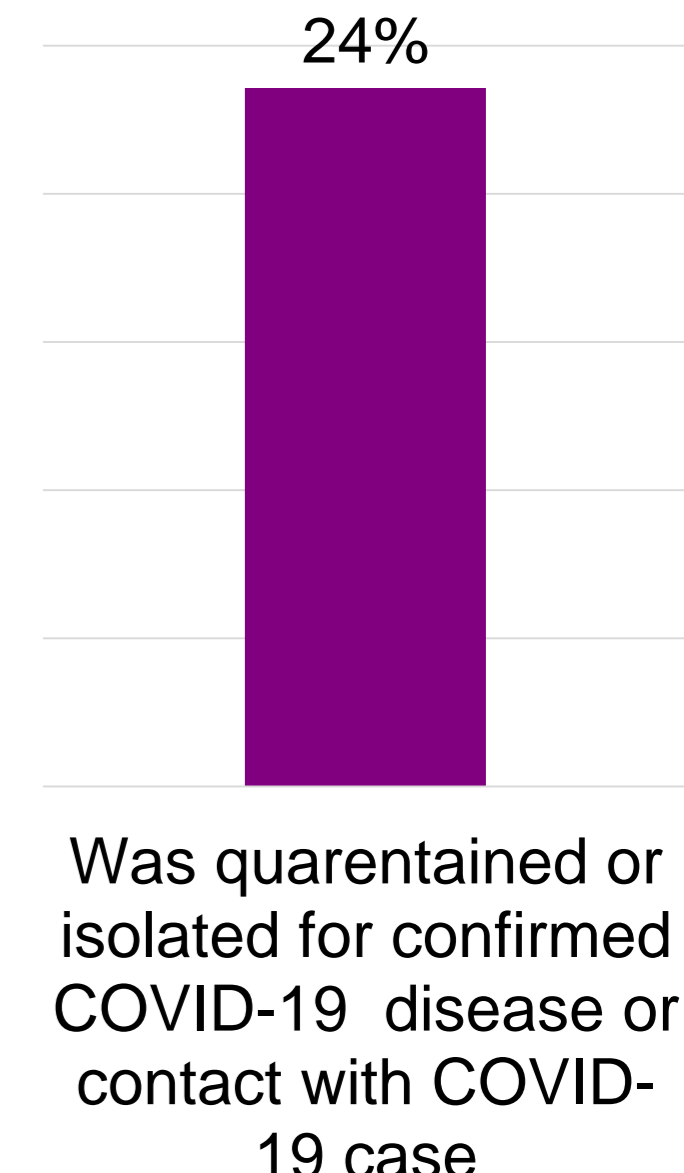
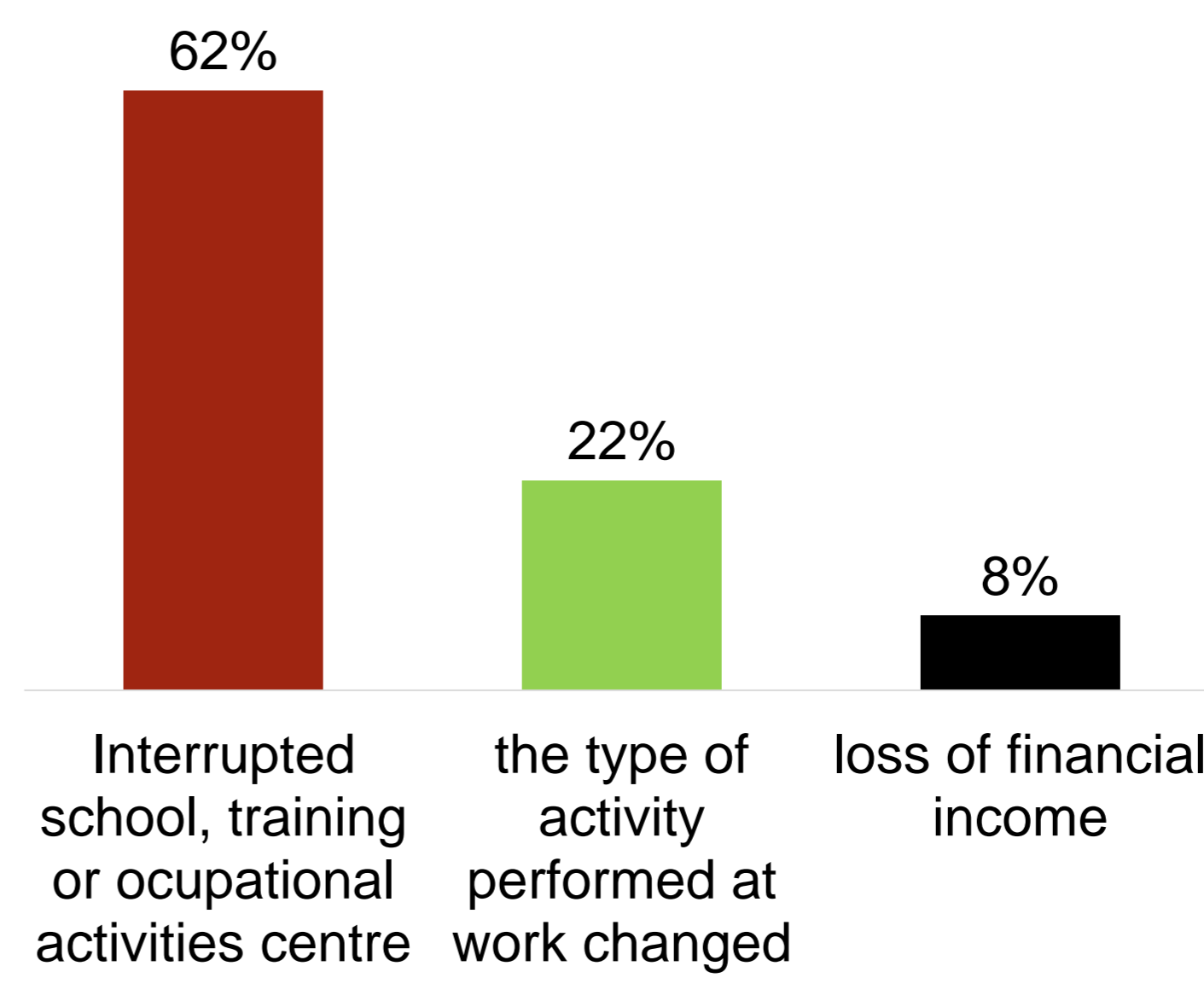
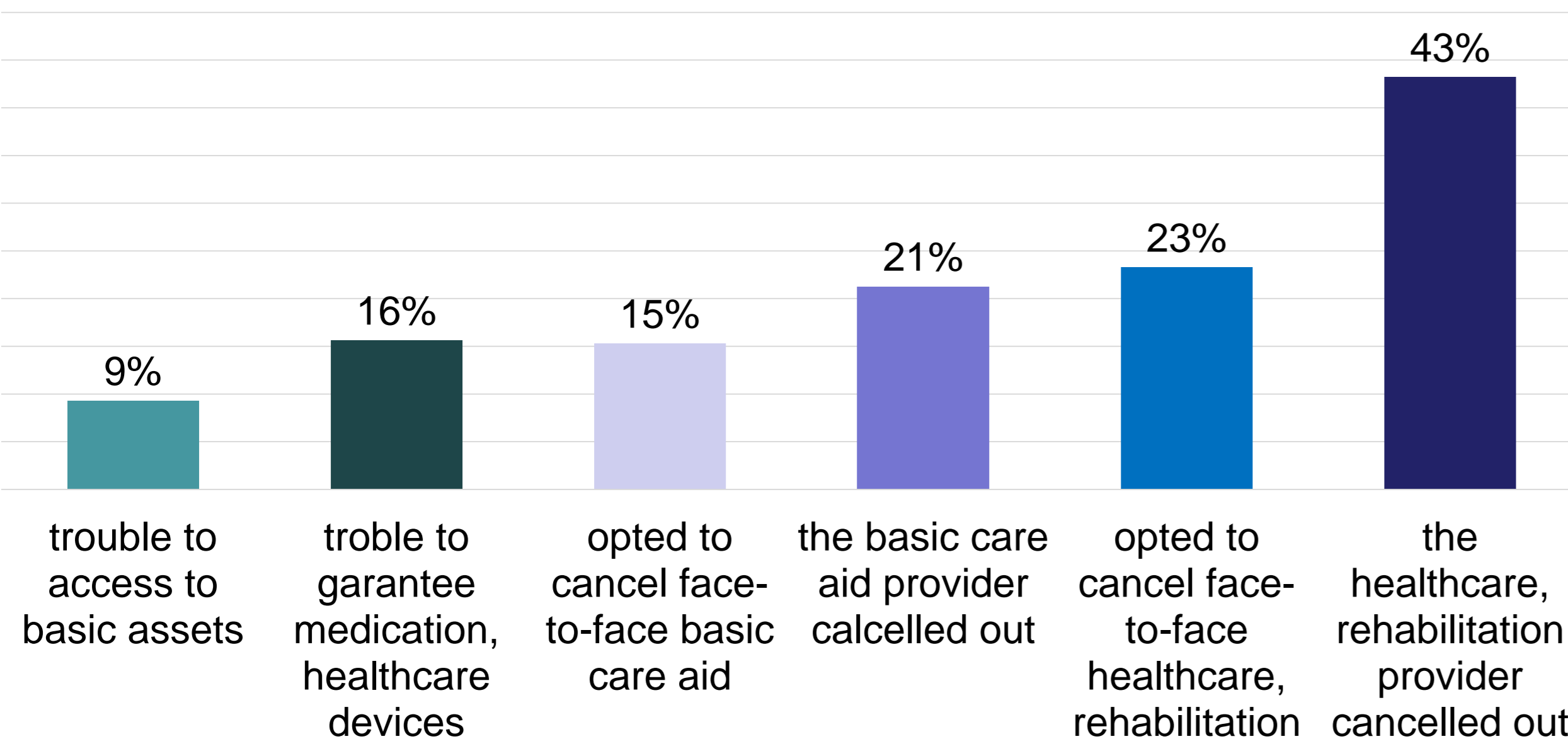
There were reported difficulties on obtaining drugs or health care related devices (16%) and, seldom, primary goods (9%); 8% reported loss in income.

The self-perception of their own general health was reported as good/very good by 71% and of mental health by 69%.

Number of entries by condition of those living with cerebral palsy



Self-reported condition of people living with cerebral palsy that participated in the prospective survey.



Self-reported disruption of the daily life of people living with cerebral palsy that participated in the prospective survey.

Conclusions/Significance

The pandemic seriously affected both social participation and the maintenance of required care and assistance of people living with CP, potentially endangering their acquired abilities, competences, wellbeing and quality of life, directly and through the instability of their caretakers.

