



Personalized Medical Information Cards for Adults with 22q11.2DS

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Background: Individuals with 22q11.2 deletion syndrome (22q11.2DS) often have intellectual disabilities, learning difficulties, and multiple health issues. They require specialized care throughout their lives, and they and their caregivers face challenges in recalling their medical histories. Interactions with health care and other professionals who are unfamiliar with their conditions may thus be complicated by an absence of important medical information. To facilitate these encounters, we made personalized medical information cards (PMICs) that contained contact and medical information for our adult patients. Using a survey, we evaluated how the patients and their caregivers used the PMICs during a pilot phase. **Methods:** For each participating patient, clinic staff generated a PMIC in the form of a credit card-sized, laminated card. Thus, information access does not require equipment or electronic health records. The front of the card contains crucial contacts, while the back lists physician-verified information including health conditions, medications, and allergies. A survey (3 scoring and 3 open-ended questions) assessed how patients and caregivers used the cards. We used non-parametric tests to determine whether card usage was affected by a patient's sex, age, living arrangement, or the elapsed time before completing the survey. **Results:** We evaluated PMIC usage for 32 patients (mean age 29.5y, 18 females). 29/32 (91%) patients (or their caregivers) completed the survey, and 12/29 (41%) reported use of their cards (over median 4 months; range 2-14) during encounters with doctors, pharmacists, or paramedics. Patients and caregivers commented that the card provided the information they needed, gave them peace of mind, sped up interactions with professionals, and avoided repeat story-telling. Card usage was not influenced by sex, age, or elapsed time before survey. **Conclusions:** The PMIC has no requirement for electronic readers, and information on it can be read quickly in both urgent and non-urgent situations. Patients and caregivers who used the PMIC found it helpful in transmitting information to healthcare providers and other professionals who assist them. Beyond the pilot phase, our Clinic continues to generate and update PMICs for patients. Further research will assess ways to improve the PMIC as a convenient communication tool for medical information.