Published in final edited form as:

J Appl Res Intellect Disabil. 2020 November ; 33(6): 1534–1540. doi:10.1111/jar.12747.

Personalized Medical Information Card for Adults with 22q11.2 Deletion Syndrome

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Abstract

Background: Many individuals with intellectual disabilities and their caregivers struggle to provide accurate and complete information to health care providers.

Method: We provided personal medical information cards (PMICs) containing contact and medical information to 52 Canadian adults with 22q11.2 deletion syndrome, a genetic condition associated with intellectual disability. We invited them and/or their caregivers to complete a survey concerning usage of the card.

Results: Forty-eight (92%) patients or their caregivers completed the survey. Twenty-two (46%) respondents used the PMIC over a median of 8 months during encounters with doctors and other professionals, and a majority of these used it more than once. Users reported finding the PMIC “very helpful” (86%) or “helpful” (14%), providing necessary information, speeding up interactions with professionals, and helping avoid repeat storytelling.

Conclusion: Providing a PMIC to individuals with intellectual disabilities and their caregivers could help improve patient safety and assist in advocacy.

Keywords

Personalized medical information card; 22q11.2 deletion syndrome; intellectual disability; multisystem condition

INTRODUCTION

22q11.2 deletion syndrome (22q11.2DS) is an as yet under-recognized genetic multisystem condition associated with physical and mental health manifestations including but not

limited to congenital heart defects, hypocalcaemia, hypothyroidism, seizures, anxiety disorders, and schizophrenia (Bassett *et al.* 2011). Mild intellectual disability (ID) is present in approximately 30–40% of individuals with 22q11.2DS (reviewed in Fung *et al.* 2015). Many affected individuals need specialized care from multiple medical professionals throughout their lives Fung *et al.* 2015.

Polypharmacy secondary to multiple co-morbidities is common in 22q11.2DS and may be associated with problems such as drug-drug interactions, drug-condition interactions, drug duplications (Payne 2016), and prescription errors.

Most individuals with 22q11.2DS are unable to provide accurate and complete information at medical appointments, and even caregivers who attend with them may have difficulty remembering all patients' conditions and medications. Repeat story-telling is a major source of frustration in caregivers (Nicholl *et al.* 2014). In addition, treating physicians may be unfamiliar with 22q11.2DS (Palmer *et al.*, 2018), which may especially be the case when patients are travelling or are in medical emergencies. Insufficient communication between hospitals, specialists, and primary care providers can affect the quality of care patients receive (Health Quality Ontario, 2018). Therefore, patients and caregivers may need an easily accessible way to provide medical professionals with relevant information. We hypothesized that personalized cards that patients can carry in their wallets are a straightforward way for them to convey accurate medical information in medical encounters. Here, we report on a survey that evaluated the helpfulness of such a clinic-issued personalized medical information card (PMIC) in adults with a 22q11.2 deletion and their caregivers.

METHOD

Clinical setting and participants

[Clinic name, hospital name, city, country] provides adult 22q11.2DS patients and their families with care from a multidisciplinary team from the fields of cardiology, endocrinology, psychiatry, neurology, genetics, social work, and nutrition with expertise in 22q11.2DS. Patients were referred to our clinic by family physicians or specialists who had been taking care of them. Our Clinic obtains extensive, lifelong medical records of patients. These include hospitalizations, consultations, relevant tests results, and prescription histories from all previous and current medical providers. Our patients have follow-up, multidisciplinary appointments at our Clinic approximately once a year, and more frequently if needed.

The PMIC was offered to patients at no cost as a quality improvement initiative of the Clinic, and as such needed no consent and formal approval from the research ethics board. Our physicians and social worker recommended patients who had ID, complex health issues, multiple allergies, long lists of medications, or language barriers to use a PMIC. The staff member in charge showed potential participants a blank sample of the PMIC, listed the contents of the card, and mentioned the advantages of having such a card when travelling or in emergencies. Patients or their caregivers then decided whether to participate or not. From September 2014 to June 2018, we made PMICs for 52 patients (25 females), including a

mother-daughter pair and a father-son-daughter trio. All patients had a molecularly confirmed 22q11.2 deletion (Weksberg *et al.*, 2007).

Generation of the PMIC

The credit card-sized PMIC was designed to display information most needed in a medical encounter. The front contained the patient's provincial health insurance number as well as contact information of family members, caregivers, the family doctor, the pharmacy, our Clinic, and the medical records department of our hospital. The back contained primary health concerns, current medications (not including dosages), any problems of non-compliance, as well as allergies and sensitivities (Figure 1). The patient's medical records were reviewed (in 20–45 minutes) by one of the Clinic's physicians, who clarified inconsistencies or uncertainties and determined the subset of symptoms that would be included on the PMIC.

Evaluation of the helpfulness of the PMIC

To assess whether the medical information card was perceived to be helpful, we conducted a brief survey with three closed-ended and three open-ended questions (Figure 2). We invited patients who had been issued their PMIC for at least two months to take part in this survey in person, via phone calls, or through emails. For patients who were unable to fill out the survey ($n=29$; 60%), the caregivers completed it on their behalf. Results for all questions as well as any additional comments received in person, via phone calls, or through emails were recorded. Patients (or caregivers) who did not respond to phone or email messages more than three times over six months were considered non-respondents for the survey. A summary of the demographics of the respondents is provided in Table 1.

RESULTS

Respondents

Of the 52 card recipients, we received 48 (92%) completed surveys from 19 patients and 29 caregivers. One family was not contacted for the survey because the patient had died within months of receiving the PMIC. The median elapsed time between receiving the PMIC and completing the survey was 8 (range 2–21) months.

PMIC usage

Twenty-two (46%) of the 48 patients and/or their caregivers had used the card at least once with doctors, pharmacists, imaging technicians, paramedics, school counsellors, or social agency representatives. Fifteen (68%) card users used it more than once. Nineteen (86%) of the users found the PMIC to be “very helpful” and the remaining 3 found it “helpful”. Seven users (32%) used it during emergencies, 15 (68%) at non-emergency medical situations, and 5 (23%) at non-medical situations (Table 2). For at least one family, when the patient required medical attention, the card was used multiple times within several weeks. Forty patients (83%) or their caregivers “always” carried the PMIC, 6 (13%) “most of the time”, and for 2 patients the answer concerning usage was left blank. Six (13%) patients reported loss of their PMICs.

Although we did not systematically collect information about reasons for not using the PMIC, one father specifically said his family did not need to do so because the patient was healthy, and six respondents reported that they never had the opportunity to use it.

Perceived helpfulness of the PMIC

The PMIC was perceived to be helpful in four main ways. First, some patients and caregivers said that the PMIC had possibly improved their safety including preventing medication duplication and/or allergic reactions. Unexpectedly, the PMIC also improved personal safety. Upon encountering a wandering patient with mild ID, customers at two coffee shops used the information on his PMIC to contact the parents, who picked the patient up. Second, the PMIC was said to provide convenience to patients and caregivers. For example, multiple patients and caregivers had used the PMIC as a reference when they filled out forms for school, work placement, and medical appointments. Some caregivers said they had used the PMIC to communicate patient information instead of repeating it to professionals. Thirdly, the PMIC had helped our patients explain their condition to others. Lastly, some caregivers noted that the PMIC had given them peace of mind. The patients and caregivers' responses to the open-ended questions are provided in Tables 3 and 4.

Meeting the needs of the patients and caregivers

Suggestions by the respondents for improvements to the PMIC included adding the home address, the list of medical specialists involved, a photograph of the patient, and the make and serial number of implanted heart valves.

DISCUSSION

We report on a survey, with high response rate (92%), that assessed the helpfulness of the PMIC in adults with a 22q11.2 deletion and their caregivers.

As with other previously reported PMICs that were developed for other complex medical conditions such as sickle cell disease (Neumayr *et al.*, 2010), most card users found the card "very helpful" or "helpful". Examples of perceived helpfulness by the respondents included patient safety (such as preventing medication duplication and/or allergic reactions), convenience, and peace of mind. Notably, nearly half reported use of the card within a median 8 (range 2–21) months during encounters with doctors, pharmacists, imaging technicians, paramedics, school counsellors, or social service agency representatives.

One advantage of our PMIC in comparison with commercial medical record retrieval systems is that commercial versions often require registration fees and/or ongoing subscription fees. Professionals receiving the information also need to call the companies (which requires a phone network) or log onto the companies' websites (which requires connection to the Internet) to access patients' medical information. Some local emergency response services in Canada offer blank forms for individuals to complete, thus giving users flexibility to write in information of their choice at their convenience. However, the information is frequently not verified by physicians. The opposite aspect is that physicians spend a significant amount of time on reviewing the charts, clarifying inconsistencies or uncertainties, and determining the subset of symptoms that would be included on the PMIC

Multiple medical providers have used information technology (IT) in the generation of various medical information cards (e.g. Neumayr *et al.*, 2010; Olola *et al.*, 2011a & 2011b). In Australia, Mohd Rosli *et al.* (2009) surveyed potential users for the perceived advantages and disadvantages of a health smart card, defined as “a smart card containing the cardholder’s electronic medical records”. Patients and emergency department staff felt the cards would be useful in emergencies, save patients’ time, improve accuracy and communication, help avoid confusion, and decrease staff workload. However, concerns included issues related to privacy, confidentiality, security, and inaccuracies. In Canada, the province of Quebec cancelled its plan for the health smartcard in 2002 because of a change in spending priorities (Pinker, 2002), and there is no large-scale health smartcard program known to be in use in Canada as of September 2019. In the province of Ontario, there are 14 approved Electronic Medical Record (EMR) systems (OntarioMD Inc., 2019) as well as 228 hospital sites (Health Quality Ontario, 2018). Generating a “smart card” that is interoperable in all existing EMR systems at all hospital sites would be a significant challenge.

After the PMIC program started, we were informed of the “22q-Ordination App” developed by the 22q Foundation Australia & New Zealand (Kamper, 2018; 22q Foundation Australia and New Zealand, 2018). This is a smart phone-accessible, Internet-dependent computer portal, with functions designed to let individuals and families digitally coordinate and share their medical reports, appointments, and profiles. However, the many options this app offers may make it too complex to use for some of our patients with ID.

Limitations of the study include the fact that our study did not systematically investigate the reasons for not using the cards. We have also been limited by the relatively small sample size and the fact that all PMIC recipients were patients of one clinic, reducing generalisability of findings. Furthermore, the generation of each individual’s PMIC was only possible after the foundation of information had been built by Clinic team members. Staff members spent hours obtaining and organizing patients’ medical records from various hospitals, testing facilities, and pharmacies, and the Clinic physicians conducted thorough reviews of these records. The comprehensiveness of patient records and the dedication of manpower may be difficult to achieve for other clinics.

Conclusion

Our survey suggests that a credit card-sized laminated paper PMIC is a helpful and convenient method for the communication of medical information for adults with a 22q11.2 deletion until such time as EMR systems are available, are facilitated to engage safely with cell phone health apps, and are adapted for individuals with ID.

ACKNOWLEDGEMENT

The authors thank all the patients and caregivers who completed the PMIC user satisfaction survey and provided feedback. We also thank Tracy Heung for providing the demographic information of the participants, and the team members of the Dalglish Family 22q Clinic for their support.

SOURCE OF FUNDING

This work was supported by the Canadian Institutes of Health Research (MOP #97800, MOP #111238), Dalglish Chair, the National Institute of Mental Health (U01 MH101723-01(3/5)), a McLaughlin Centre Accelerator Grant, the Canadian Research Chairs (CRC) Program, and other sources over the past 30 years.

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MEDICAL INFORMATION CARD

Name: _____ Date of birth (dd/mm/yyyy): _____

Phone #s: _____ OHIP number: _____ Medical Records # (MRN): _____

Emergency contact: _____

Family Physician: _____

Pharmacy: _____

For further information, please call _____

For after hours assistance, please call _____

This card was last updated (dd/mm/yyyy): _____

has 22q11.2 Deletion Syndrome
(Previously known as DiGeorge or Velo-cardio-facial syndrome).

Primary health concerns: _____

Medications _____

Allergies or sensitivities: _____

Note: The information on this card is subject to change

1. The front (left) and back (right) of a blank version of the personalised medical information card (PMIC).

1. Did you use your medical information card during a medical encounter? (Describe encounter if possible: e.g. Who was the medical personnel (specialist? Emergency doc? Family doc? Other health care providers)? What information was needed from the card?)

2. Was the medical information card helpful in that encounter? (Please circle the number)

Not helpful at all	Not really helpful	Don't know	Helpful	Very helpful
1	2	3	4	5

3. Did you use your card more than once? (If yes, repeat #1 and #2 for all encounters)

4. What other information would you like to see on your card?

5. How often do you carry your medical information card with you when you go out? (Please circle the number)

Never	Once a month or less often	Once a week or less often	Most of the time	Always
1	2	3	4	5

6. What is the current condition of your card? (Please circle the number)

Lost	Damaged and unusable	Damaged but one can still read all the text	Slightly wrinkled	As good as new
1	2	3	4	5

Thank you very much for your time.

2.

Survey for the helpfulness and durability of the personalised medical information card (PMIC)

Table 1:Demographics of the 48 respondents of the PMIC^a satisfaction survey

<i>Respondent information</i>	
Gender = female	23 (48%)
	25 (17 to 63)
Median (range) age when receiving first card	years
Family member or caregiver as respondent	29 (60%)
Median (range) elapsed time between card & survey	8 (2 to 21) months
<i>Health conditions, medications, dependency</i>	
Median (range) # health conditions	11 (3 to 23)
Median (range) # medications	7 (1 to 19)
Dependent (lives with family member or caregiver)	36 (75%)
<i>CHD^b</i>	
No CHD	22 (46%)
Simple CHD	7 (15%)
Moderate CHD	12 (25%)
Complex CHD	7 (15%)
<i>Psychosis</i>	
Non-psychotic	30 (63%)
Schizophrenia	12 (25%)
Psychotic mood disorder	6 (13%)
<i>Intellectual functioning</i>	
Average	5 (10%)
Borderline ID ^c	13 (27%)
Mild ID	27 (56%)
Moderate ID	3 (6%)
<i>Card usage</i>	
Used card at least once (% of survey respondents)	22 (46%)
Used more than once (% of card users)	15 (68%)

^aPMIC, personalized medical information card^bCHD, congenital heart disease^cID, intellectual disability

Table 2:

Usage of the PMIC

Situation for Card Usage	Number ^a and percentage ^b of card users
Emergency department / paramedics	7 (32%)
Non-emergency medical situations(including with pharmacists, dentists)	15 (68%)
Non-medical situations (includes filling out forms for schools or social agencies)	5 (23%)
Did not specify	1 (5%)

^a
n=22

^b
Percentages can add up to >100% because patients and caregivers used the PMIC for more than one purpose.

Table 3

Patients' responses for survey question #1 and their comments on PMIC usage.

Comment
"Not a lot of people know about 22q. They are dumbfounded. Even my disability worker did not know about 22q, so I just let her see the card to read up about it."
"I forgot my health card at home and needed my healthcare number for a medical appointment."
"When I used the card in emerg it was to show details of my condition. Most people don't know what 22q is. I also used it to show them my allergies."
"I just had to say my medication was on the back of the card. Didn't have to show them or tell them so many times or the same thing especially when I was in distress."
"To look at allergy information and emergency contacts while filling out the form for school and co-op placement. Sometimes I can't remember how to spell penicillin."

Table 4

Caregivers' responses for survey question #1 and their comments on PMIC usage.

Comment
The card is "useful. It lists [the patient's] allergies to medications, which I sometimes forget."
"I don't need to repeat the info. Everything is on the card."
"It's perfect. It works well."
"I do feel good that he has it with him as he is in school in [a different city] during the week."
"He is very timid about letting people know what he has, especially strangers. I do still feel it is important for him to have as he goes to college and may need to use it some time."
"Sometimes we don't remember the meds or don't have all the info together, but the card has everything."
"That card has been a God-send."
"Having the card made the experiences with the endocrinologist and the counsellor faster."
"I don't have to repeat myself. Also, [another hospital's] records are not as extensive as [our clinic's] records."
"The card is great to have while [patient] is out in his day program as well as his Thursday evening [activity]. It is wonderful to know that it is with him at all times."
"I used it at the dentist when he wanted to know the medication my son was on."
"On occasion as parents we are in a situation that our emotions run high and giving them the card is so simple. The card carries key information, the diagnosis (which most physicians have never heard of), doctors and hospital information."
"Love this card...I am going to try and speak to [another family member's] counsellor at [another medical centre] for them to introduce this for their clients. We recently had an issue in emerg...If their diagnosis and meds would be on there, it would alleviate a lot of stress for both parties."