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Feasibility of "Symptom Discovery," a Longitudinal and Comprehensive Data Collection Tool During COVID-19

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Abstract. There are few patient- or public-facing tools for longitudinal and comprehensive symptom assessment, especially when faced with an uncharacterized condition such as COVID-19 or a chronic condition in which symptoms have not been adequately specified. To address this need, we developed the Symptom Discovery mobile application and tested its feasibility with the US public early in the COVID-19 pandemic. Although there were challenges, results showed feasibility and acceptance.

Keywords. Symptom tracking, COVID-19 pandemic, mobile health, feasibility assessment

1. Introduction

In the early months of the COVID-19 pandemic the clinical presentation and symptoms were unclear. The rate of asymptomatic or pre-symptomatic human-to-human transmission of adults ranged between 18% to 62% [1,2]. However, reports focused on common symptoms such as fever and cough, which were later found to be inadequate for screening [3]. Self-report is an important source of data for characterizing potential infection, given the diversity of signs and symptoms that may be present and their changes over time. Self-report combined with artificial intelligence shows promise for earlier detection and better management of COVID-19 [4] and prognosis prediction [5]. There are few patients or public-facing tools for longitudinal and comprehensive symptom assessment, especially when faced with an uncharacterized condition such as COVID-19 or a chronic condition in which symptoms have not been adequately specified. To address this gap, we developed a mobile application and tested its feasibility with the

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public early in the COVID-19 pandemic.

2. Methods

Multidisciplinary team members (faculty, graduate and undergraduate students, and patient representatives) with expertise in computer science, medicine, nursing, and informatics worked together to design and build a mobile application entitled "Symptom Discovery."

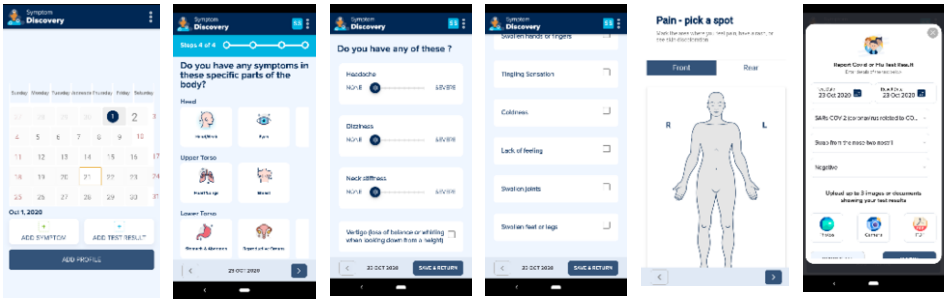

Figure 1. Symptom discovery app screenshots.

Participants were recruited via a university website, Twitter, and paid advertisements on Facebook from February 17, 2021 to June 30, 2021. Advertisements were designed to recruit diverse individuals and multi-generational families. Eligible participants were US residents, English reading, and 13 years or older (Participation of 13 to 18-year-old adolescents required parent/guardian consent). Adult participants could also register a minor and enter results on the minor's behalf. Participants received up to $60 based on the number of days of participation. The study was approved by the UC Davis Institutional Review Board #1696552-2. The app contained three surveys. *Demographic and Health Survey:* a one-time survey documenting demographic characteristics and comprehensive health history). *Daily Symptom Survey:* a comprehensive symptom survey offered daily for up to two months with three guided modes of data collection: a) an image of the body to identify locations of pain and skin-related symptoms; b) structured questions organized from head to toe with opt-in for each area of the body (a total of 129 items) as well as measurements of temperature, pulse, blood pressure, oxygen saturation; and c) a free-text comments section to describe symptoms or other information that was not captured in the structured questions. *Lab Test Survey:* a site for test results for COVID and influenza, including date of the sample collection, sample collection method, lab result, date of the result, and attachment of test report if available. Participants were given an email and phone number to call for technical support which was monitored during normal working hours by a research assistant.

3. Results

Out of 135 initial enrollments, 118 individuals completed the demographic survey (Table 1). Close to half of all participants had completed at least college, and most were female-

identifying. Over half of the participants identified as a member of a racial or ethnic minority group. One African American and one Native Hawaiian or Pacific Islander enrolled in the study. Table 2 describes the present and past health conditions of participants. The only condition affecting a majority of the sample was hearing/eye conditions. Other common conditions are infectious disease and heart and blood conditions.

Table 1. Demographic characteristics.

Characteristic	Number	%
Education (n=118)		
Less than a High school Graduate	8	6.78
High School Graduate	8	6.78
Some College or Technical School	42	35.59
College Graduate	30	25.42
Postgraduate	28	23.73
None (e.g., infant)	1	0.85
Prefer not to State	1	0.85
Biological Sex (n=118)		
Female	93	78.81
Male	22	18.64
Intersex	2	1.69
Prefer not to state	1	0.85
Gender Identity (n=118)		
Female	91	77.12
Male	21	17.8
Non-binary	2	1.69
Prefer not to state	2	1.69
Transgender	2	1.69
Race/Ethnicity (n=118)		
White, not Hispanic/Latino	55	46.61
Asian, not Hispanic/Latino	33	27.97
Hispanic, Latino, or Spanish	21	17.8
American Indian or Alaska Native	2	1.69
Black or African American, not Hispanic/Latino	1	0.85
Middle Eastern or North African	2	1.69
Native Hawaiian or Pacific Islander	1	0.85
Other	2	1.69
Prefer not to state	1	0.85
Health Insurance (n=118)		
Yes	113	95.76

At least one symptom survey was completed by 89 participants (3 child profiles were created by a parent/guardian). The total number of symptom surveys completed was 2,707. The mean number of surveys per participant was 30.42 (SD 28.31, range 1-95). The median duration of symptom data collection, defined as the length of time in days that a participant entered data, was 45 days (m = 44.72, SD 28.31, range 1-380). Fifty-one (51) participants entered lab tests. The total number of tests reported was 247. The mean number of tests reported per participant was 4.84 (SD 6.24, range 1-27). Thirteen participants uploaded an image or pdf copy of their test document, while the remainder self-reported a result without uploading an image. Eleven participants reported at least one positive COVID/influenza/Unknown test result. In addition, 25

people reported that their sample was collected from saliva, and another 25 reported collection by swab from two nostrils. One person reported that the sample was collected from the throat or mouth, and one person was not sure. There were only a handful of requests for help, and the issues were easily resolved by answering a usage question.

Table 2. Health History.

Health History	Number	%
Heart and Blood Conditions (n=112)	37	33.04
Lung conditions (n=111)	33	29.73
Cancer (n=109)	12	11.01
Digestive conditions (n=109)	28	25.69
Hormone/endocrine conditions (n=109)	20	18.35
Kidney conditions (n=109)	3	2.75
Bone, joint, muscle conditions (n=109)	24	22.02
Hearing and eye condition (n=109)	63	57.80
Infectious diseases (n=109)	44	40.37
Brain and nervous system conditions (n=109)	19	17.43
Obesity (n=74)	20	27.03
Skin condition (n=74)	24	32.43

4. Discussion

The use of apps for symptom surveillance in public health purposes such as tracking influenza over time pre-date COVID-19 [6]. Public-facing tools proliferated for COVID-19 symptom data collection but many of these tools [3,7] were focused on a pre-determined CDC-recommended symptom list. One such app [7] collecting longitudinal symptom data from more than half million users noted symptoms overlapping among people with positive or negative covid tests, which implies a limitation of using only the common symptom list provided by the CDC. Thus, we demonstrated an innovative approach that allowed for assessment of the whole body via three modes: the selection on a body graphic, symptoms ratings on a Likert scale, and multiple-choice questions along with a place for any additional reporting. We have witnessed the importance of a more flexible and longitudinal approach to symptom discovery as new signs and symptoms have emerged throughout the pandemic, such as ageusia [8], urticarial eruption [9]. In addition, longitudinal data collection of symptoms has identified a panoply of indicators grouped together as a syndrome referred to as long COVID [10]. In addition, we demonstrated that longitudinal data collection was feasible, with a median duration of 45 days. A recent review supports the feasibility of mobile app-based data collection from 1 to 12 months [11]. In our study. The use of incentives prorated on the duration of data collection may have contributed to active participation. The small number of technical support requests and a large number of data points entered together suggest the usability of the app was adequate.

This study was limited due to the small sample size and the limited number of participants who entered positive COVID results and potentially COVID-attributable symptoms. Thus, we do not report on the symptoms or relationship to COVID-19 illness. Although the sample was racially/ethnically diverse, it was biased toward highly educated and female, a common issue with similar studies [12]. While the research team was diverse and social media recruitment attempted to reach diverse participants, further research should pay greater attention to the multi-dimensional aspects of diversity.

5. Conclusions

Our study highlighted some insights into the methodological aspects of longitudinal and complex symptom data collection via a mobile application. First, the collection of complex signs and symptoms over long periods of time is feasible, at least when modestly compensated and in a comparatively advantaged population. This approach was demonstrated early in the COVID-19 pandemic but may be useful for symptom research regarding other important public health and medical challenges, such as emerging infections and chronic conditions for which rigorous collection of symptom data has not occurred. It can also contribute to monitoring efforts when both the causative infectious agent and the symptoms it produces evolve over time.

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