

Evaluation of MeTree for Family Health History Collection in Sri Lanka

Ruoyu Hu¹, Vijitha De Silva², Lori Orlando³, Truls Østbye⁴

¹Graduate of Master of Science in Global Health Program at Duke Global Health Institute, currently based in Kunming, Yunnan province, China. ²Professor in Community Medicine, Faculty of Medicine, University of Ruhuna, Sri Lanka. ³Professor of Medicine; Duke University Center for Applied Genomics & Precision Medicine, Durham, NC, USA. ⁴Vice Chair, Research, Department of Family Medicine and Community Health, Duke University School of Medicine, Durham, NC, USA.

Abstract

Introduction: Information about family history of illnesses including hereditary cancers is increasingly important to ensure each patient receives optimal health promotion advice, preventive health services and appropriate screening or treatment. MeTree is an American, validated, web-based family health history based risk assessment tool that collects data directly from patients. Little is known about its utility in countries with different disease profiles, health care infrastructure and policies, and cultural and socioeconomic contexts. **Methods:** This study enrolled 304 medical students from the University of Ruhuna in Sri Lanka. Participants constructed family pedigrees and entered their information into MeTree, as well as completed a paper-based questionnaire asking about their experience with and perceived benefits of MeTree. **Results:** 3302 records and 87 different diseases were entered into MeTree for all index participants and their relatives. Diabetes was the most common disease reported and accounted for 24.6% of all diseases reported. The mean time to enter information into MeTree was 36.3 minutes. Questionnaire responses indicated a high level of satisfaction with the use of MeTree and the perceived benefit was high. No significant difference was observed in completion time or survey responses by age or gender. **Conclusions:** Most medical students found MeTree easy to complete and considered it a useful experience. The majority thought it possible to generalize MeTree to the context of Sri Lanka, though barriers, such as limited internet access, will need to be addressed to integrate a web-based tool, like MeTree, into routine practice in Sri Lankan clinics.

Keywords: Family health history- MeTree- Cancer screening- Disease occurrence- Participants' experience- Usefulness

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Introduction

Family health history is a record of the diseases and health conditions in one's family [1]. Identification of family histories demonstrating a hereditary disease pattern is important for presymptomatic disease screening and detection [2] for cancer as well as other illnesses. Many guidelines for screening and prevention rely upon risk assessment using family health history to guide the appropriate use of alternative screening procedures or genetic counseling, and strongly recommend that not only genetic disease specialists, but also primary care providers, collect family health history for disease risk stratification and risk management [3-5].

MeTree is a patient-facing, web-based tool developed by Duke University, the University of North Carolina Greensboro, and Cone Health System, in a collaboration known as the Genomedical Connection, to collect family health history from primary care populations [6]. MeTree is designed to collect family and personal health history directly from participants through a website and can be completed by participants on their own. It can also be used to support clinical decision-making for genetic assessment. The benefits of using MeTree include reducing burdens on providers, improving quality of data collection by involving patients and their whole family, improving

Corresponding Author:

Dr. Vijitha De Silva

Vijitha De Silva, Professor in Community Medicine, Faculty of Medicine, University of Ruhuna, Sri Lanka.

Email: pvijithadesilva123@yahoo.com

quality of care by providing information on risk for multiple diseases and recommendations for screening and prevention, as well as promoting patient participation in care [7].

Previous studies indicate that MeTree can be effectively implemented in diverse primary care settings in the US and can effectively engage both patients and providers [8]. However, little is known about MeTree's utility in countries with different disease profiles, health care infrastructure and policies, and cultural and socioeconomic contexts. To generalize the use of web-based tools like MeTree, the patterns of data collected by these tools need to be clarified, and the feasibility of implementation in low-resource settings should be evaluated.

The aims of this study were to evaluate the utility and feasibility of using MeTree for family health collection in the context of Sri Lanka, and to tabulate the frequency of reported diseases to determine if these data could be captured satisfactorily through MeTree.

Methods

• □ *Settings and Participants*

This study was conducted June to August 2018 at the University of Ruhuna, located in Galle, Sri Lanka. Participants were all medical students at the Faculty of Medicine. The inclusion criteria for the participants were: ≥ 18 years old, and able to read and speak English. Recruitment target was ~ 300 . Participants were compensated with 500 Sri Lankan Rupees (approximately \$3USD) each.

• □ *Procedures*

All participants gave informed consent. After consenting, participants were given a letter introducing MeTree and the type of information that would need to be entered. The letter also included a worksheet, which helped participants collect family health histories from their relatives at home. A few days later they came back to enter their family health histories into MeTree, with help from the researcher and a local research assistant, in a faculty computer lab. The time it took to enter the participants' family health history was recorded. Based on the entered data, a report was generated showing diseases participants might be at increased risk for, and, therefore, might want to talk to their doctors about.

After receiving their report, participants were asked to complete a questionnaire about their experience with MeTree and any perceived benefits. The first 4 questions in the questionnaire asked about participants' gender, age, major, and grade. The remaining 15 questions asked about their overall feelings about MeTree, their experience with MeTree, and the perceived benefits of using MeTree.

• *Analysis*

Family health history pedigree data entered into MeTree was stored in a SQL database and analyzed using SAS statistical software. Frequencies of 21 disease categories were calculated for all individuals, then for index participants and relatives separately. The paper-based

questionnaires were kept securely in the Faculty of Medicine, and data collected using questionnaires was entered into RedCap by the researcher right after the data had been collected. Descriptive statistics were used to summarize participants' demographic characteristics and answers to each question. Mean and standard deviation (SD) were calculated for the time used to complete entering all information into MeTree.

Results

• □ *Characteristics of Participants and Their Relatives*

"Three hundred and four (304) medical students" participated, with a median age of 25; 47.4% were females. Family health histories were entered for 3352 relatives in total, i.e. the mean pedigree size was 11 (range 7-30). Most relatives were parents and grandparents.

• □ *Disease Occurrences*

The total records entered into MeTree for all index participants and their relatives were 3308, and 87 different diseases were present among all participants and relatives. The individual diseases were categorized into 21 disease groups according to the pedigree of diseases developed by the MeTree team. The most commonly reported disease was diabetes, followed by hypertension and cardiovascular disease. Relatives had much higher "prevalence" of all disease categories compared to the index participants. Percentage of relatives accounted for the reported disease were all higher than 80% except for digestive disorders. Among the index participants, the most common disease was lung disease with a prevalence of 6.6%, followed by eye disorder (5.9%) and digestive disorder (4.9%). In contrast, among the relatives, the most common diseases were diabetes (24.2%), hypertension (14.3%), and cardiovascular diseases (11.8%). Cancers were reported with lower frequencies among both the relatives and index participants. The overall percentage of cancer reported for both the index participants and the relatives were 6.86%, of which 96.48% were reported for the relatives. The prevalence of cancer was much lower among the relatives (6.53%) than that among the index participants (2.63%).

• □ *User Experience*

Three hundred questionnaires were collected from the 304 students. Proportions for each answer are shown in Table 1.

The mean time to complete MeTree was 36.3 minutes (range 10-78 minutes). No significant differences were observed in completion time or answers for each question in the questionnaire by age or gender (t-tests, ANOVA or chi-square tests, 5% significance level).

Discussion

Common diseases reported in this study generally correspond with the common diseases in Sri Lanka's country disease profile, indicating that MeTree can be used to accurately and relatively completely collect

Table 1. Experience-related Questionnaire: Responses

	Unsatisfactory	Satisfactory	Other (Neutral or Missing)
Satisfaction Level	1.7% (5/300)	96.7% (290/300)	1.7% (5/300)
	Likely	Unlikely	Other (Neutral or Missing)
Probability of recommending MeTree to others	97.7% (293/300)	0.3% (1/300)	2.0% (6/300)
Probability to generalize MeTree into Sri Lanka	94.4% (283/300)	4.3% (13/300)	1.3% (4/300)
	Yes	No	Other (Neutral or Missing)
MeTree was easy to use.	97.3% (292/300)	0.7% (2/300)	2% (6/300)
I feel comfortable when answering questions.	81.3% (244/300)	9.3% (28/300)	9.3% (28/300)
Questions were easy to understand.	98.0% (294/300)	0.3% (1/300)	1.7% (5/300)
The layout of the website is organized and clear.	95.3% (286/300)	1.3% (4/300)	3.3% (10/300)
Completing MeTree is a useful experience.	96.3% (289/300)	0.3% (1/300)	3.3% (10/300)
The worksheet was helpful.	95.7% (287/300)	1.0% (3/300)	3.3% (10/300)
I talked with relatives before using MeTree.	36.0% (108/300)	60.3% (181/300)	3.7% (11/300)
I have enough information for relatives when completing MeTree.	36.0% (108/300)	53.3% (160/300)	10.3% (31/300)
	Agree	Disagree	Other (Neutral or Missing)
Completing MeTree made me more aware of health risks	94.3% (283/300)	0.7% (2/300)	5% (15/300)
Knowing my family health history has changed how I think about my health.	85.3% (256/300)	1.0% (3/300)	13.7% (41/300)
The suggestions MeTree gave are helpful to me.	90.3% (271/300)	1.0% (3/300)	8.6% (26/300)
Having my family tree drawn out is helpful to me.	92.0% (276/300)	1.0% (3/300)	7.0% (21/300)

family data in Sri Lanka, at least among medical students. The significant pressure and workload these students face may partly explain why diseases such as lung disease, eye disorders, and digestive disorders are the most prominent diseases among the index participants. The difference in disease occurrences between the index participants and the relatives can mostly be attributed to the younger age of the students.

Most reported a favorable experience with MeTree and found it helpful for increasing their awareness of health risks and knowledge about family health history. Most also indicated that MeTree was easy to use, but a few may have found it difficult to enter the information given that the completion time was as long as 78 minutes. This time might have been reduced some if MeTree had been available in the local language, Sinhala.

Useful participant feedback about MeTree included: 1) Classification of "Occupation (Job)" was not very granular nor well suited to the local context; 2) Some of the diseases listed in MeTree were not common in Sri Lanka, while some local common diseases were not available in MeTree (e.g. psoriasis, fibroadenoma, liver diseases); and 3) it might be better to add a "No" or "Other" option for those diseases that were not hereditary and for when some details were not known by the participant.

Over 90% of participants indicated that MeTree would be very likely, likely, or somewhat likely to be generalized in the context of Sri Lanka. Perceived barriers to implementation in Sri Lanka were elicited through informal conversations and on the questionnaire. Based on the feedback provided, barriers to put MeTree into use in Sri Lanka include:

1. Language limitation: Most Sri Lankans are not fluent in English, so it would be difficult for them to use MeTree unless it was translated into the native languages (Sinhala and Tamil).

2. Knowledge limitation: There may be limited

knowledge about ones' own medical history. Therefore, some participants suggested that MeTree would need to be administered through medical or related professionals.

3. Equipment limitation: The availability of computers and internet is still limited, not only among the general public, but also in the hospitals and clinics.

4. Privacy consideration: Some are not willing to reveal their personal information, including medical data, even to their family members.

5. System limitations: The medical record systems in general needs to be improved. Today, most of the medical information is kept in a paper booklet with the patients rather than in the clinic. Ideally, MeTree should be an integral part of an electronic medical record system.

This study is among the first to use web-based tools to collect family health history in a resource poor country. The study illustrates the utility of web-based tools like MeTree for patients in this context, and also provides suggestions for improving and generalizing this type of tool. Further, the results can form a basis for future research on how family health history collection tools can be better optimized in settings like Sri Lanka.

Limitations of the study include that the tool was only tested among medical students. However, this was a good first step in understanding feasibility. Given our initial success and the useful feedback, our next step would be to expand testing to include the general population or specific patient populations, with some type of language support or translated version.

Patients can use MeTree to collect and organize their own family health history with the help from their providers or social health workers, when they are at home and have the time to collect and think about their family history. This will allow them to present a completed family history for their providers' reference during each visit to help the provider better understand the patients' history and their potential risk factors.

Ultimately, the diseases and conditions listed in MeTree will need to be adjusted according to the local disease profile, and it may be more accessible if it were adapted for smart phones.

In conclusions, the most common diseases among the medical students and their relatives in Sri Lanka were diabetes, hypertension and cardiovascular diseases, followed by high cholesterol and cancers. It is feasible to use MeTree for family health history collection in this context. Most medical students found MeTree easy to use and considered it useful. Change in awareness of risks and knowledge towards family health history were reported by most participants.

Barriers such as language, equipment, and health system infrastructure still remains to be overcome, before a tool such as MeTree can be put into routine practice.

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Ethics Considerations

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was granted ethical approval by the Campus IRB of Duke University and by the Ethical Review Committee of Faculty of Medicine, University of Ruhuna. This article does not contain any studies with animals performed by any of the authors.

Informed consent was obtained from all individual participants included in the study.

Patients signed informed consent regarding publishing their data in this article.

Availability of Data and Material

The datasets and material generated during and/or analyzed during this study are available from the corresponding author on reasonable request.

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