Breakout Session 2: Track B

Machine Learning and the Ethics of Use: Patient and Provider Perspectives on Utilizing Prediction Models in Medical Care

Dr. Jessica Sperling
Director, Office of Evaluation and Applied Research Partnership, Duke University

Dr. Whitney Welsh
Research Scientist, Duke University

Ethical Considerations in Predictive Modeling

Patient, caregiver, and provider perspectives on utilizing machine learning (ML) based clinical prediction models (CPMs) in medical care

Presenter: Jessica Sperling, PhD

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Project Rationale and Focus

Context

- Machine learning (ML) based clinical prediction models (CPMs) have proliferated over the past few years, becoming a central component of healthcare.

- These tools show great promise in informing both providers and patients of impending health outcomes.

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Gaps / Needs

- Within ethical implications, there is need for a better understanding of what interpretability means, even at the early design stage, and how models can be most ethically, effectively, and appropriately used in practice

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Aims

Engage a diverse set of patients, caregivers, dialysis providers and data scientists to **solicit considerations for the design and performance of a tool** to predict life expectancy to support shared decision-making.

Develop resources re: **priority factors and guidances** for developers and end users of ML-based CPMs.

R01 connection. *Current R01 develops an ML-based predictive model for life expectancy for patients undergoing hemodialysis. Current project is an ethics-focused supplement.*

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Primary Questions

1) How do end-users (patients, caregivers, providers) **perceive ML-based CPMs** as compared to other, non-ML-based, forms of prediction?

2) What factors facilitate or **underlie trust** in these models' use and/or results, and what factors prompt distrust?

3) How can **realities and complexities of the models**, including uncertainty and differential performance, be communicated to maximize interpretability, utility, and trust?

4) How do aforementioned factors **differ by specific respondent type** (patient, caregiver, provider)?

Methodology

Qualitative data collection (focus groups & interviews, approx. 90 minutes)

- **Stratification:** Five respondent types (End-user groups including 1) kidney dialysis patients, 2) caregivers, 3) medical providers, 4) non-medical providers; also 5) data scientists), with focus group stratification by respondent type

- **Sequencing:** Initial data collection with end users; results used to inform data collection with data scientists

- **Content:** Addressed views on trust in prior and newer (ML) methods, degree of information desired, data presentation, and use for decision-making

- **Format:** Included discussion questions & mock scenarios (for end-users)

Qualitative thematic analysis; largely inductive coding schema

Participants

- 52 total end-user participants, 11 data scientists participants (63 total)

- In general, intent for diversity among key characteristics achieved, though focus on nurse medical providers

- Valuable recruitment partnership from:
  - CTSI Kannapolis
  - Natl Kidney Foundation
  - MyChart / MaestroCare

	Patients	Caregivers	Medical providers	Non-medical providers	Data scientists	TOTAL
Invited to participate	30	19	25	17	16	107
Total N participated	**13**	**12**	**13**	**14**	**11**	***63***

Results: Acceptability

- Participants across groups generally **not put off** by ML as a concept

- Viewed as **valuable and/or as inevitable**, with more acceptability over time

- Concern about **ability to account for individual cases**, including ideas of outliers

- Some general **doubt about utility of mortality prediction** overall; suggested different views on prediction of non-mortality outcomes

The doctor, you know, has got in essence just what his or her experience has been, **whereas the computer model is going to pull from different populations and you know everybody's experience**.

If it's going to be in the next year I have no, no comfortability with that. If it's going to be the future, say **in five years when more information has been given and we learn more about it, then I would say yes.**

I don't know if we can account for the human experience…We can look at data using the computer model. We can look at labs. We can look at disease…[but] you can have two people with the exact same thing going on and have very different results… we can't account for that.

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Results: Construction

- Some concerns about **where data comes from**, **what is (and is not) included** in models

- Desire for health conditions data included but also **social factors and social supports**

- All participant groups expect **high accuracy rates** (80%+) for use, at least for their subgroup

- Re differential performance, participants wanted to **know about their group only**

It all depends on the **source of the data**.

My biggest trust would be **how large of a pool they're pulling from. And for how long.** Like, I mean, you have to look at information from a long time period, ten years, fifteen years, if you can go back and figure that out. I mean, the more information you have the better opportunity it is to, to predict correctly, I guess.

There are intangible factors that the computer model doesn't necessarily address or might only address later, whatever. Take for instance, how about **the question of how much family support there is, right**? If [name] is there monitoring her husband's medication then that's different from somebody who lives by themselves.

Results: Use

- Desire for use **in combination with** providers' perspective

- Providers want **information on models/factors available to them**; patients vary in amount of model information desired

- **Confusion** between accuracy rates and prediction itself

- Desire for use of ML models for **individualized prospective predictions**

- Can be used to support a **clinician giving difficult information** or to **support patients wanting different (usually less aggressive) care** than do their caregivers

I want to know what my doctor, how, **how he feels about this information.**

If I [provider] don't have an understanding of where it's [data is] coming from or how it's coming up with those numbers, **I don't think it's responsible or ethical to go and tell people that**.

I think most people would get lost **in too much information, be overload.** They need to know the data and then what does that mean to me to that individual patient.

Sometimes with our older adults if …they're on the fence …but maybe family is saying, no, doing everything, do everything, do everything. This [ML prediction] can add…I looked at this and it says, you know, what I'm not, I've decided I'm not going to start [added treatment]. **This is another piece for them to provide it to family as well as to help them with their decision making.**

Selected overall take-aways

- Overall evidence of acceptability

- Relatively minimal overt by-stakeholder differences in key areas of focus

- Areas of consideration for ethical, acceptable, and trustworthy use include:

Duration of ML model use	Data Quality	Accuracy & Differential Performance	Provider Presentation / Explanation	Patient Understanding	System-Level Use / Implications
• Whether model has been existing/tested for long enough • Whether people have been exposed to it for long enough to be comfortable	• Quality, amount, and credibility of data used in model • Limitations if factors including patients' individual treatment compliance and social support are not included	• High model accuracy needed for use • Confusion and/or negative emotions (e.g., anger) around cases of differential performance	• Whether providers have the capacity (knowledge, time) to provide appropriate and patient-desired explanation • Provider presenting data/results needed for empathy valued by patient	• How much information should be presented to patients and caregivers, with drawbacks in either extreme • Whether patients/caregivers can understand premise make-up of ML model	• Concern about use by hospital systems or insurers as a basis for denying treatment

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Key Challenges

- Recruitment & participation

- Logistics of focus group organization

- Complexity of concepts discussed

- Complexity of data

Further considerations

- How are views and use of ML-based model **distinct from existing/typical prognostic models**?

- How do views **vary by clinician type** (especially including MDs)?

- How do views **vary by factor/outcome predicted**?

- How are **institutions** (hospitals, insurers/payers) to use this information?

- Further study needed as this model **moves into practice**

Next steps

- Expansion of efforts (addressing "How are views and use of ML-based model distinct from existing/typical prognostic models?")

    Recent proposal submission for similar design focused on risk prediction in autism

- Publications in development

    Focus on a) user-oriented perspective, and b) data scientists' perspective on user desires; builds on prior presentation at Duke AI Health Seminar (Jan. 2024)

Thank you

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