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Editorial

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# Consumer- and patient-oriented informatics innovation: continuing the legacy of Warner V. Slack

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Biomedical informatics pioneer Warner V. Slack, MD (1933–2018) is widely credited with saying "Patients are the most underused resource in healthcare" in the 1970s. In a previous editorial, I highlighted the continued relevance of consumer- and patient-oriented perspectives in biomedical and health informatics.[1] Additionally, a recent American Medical Informatics Association analysis related to physician clinical informatics subspecialty practice[2] as well as existing definitions for other health professionals (eg, nursing informatics[3]) emphasize the importance of this focus. Five articles in this issue reflect innovative biomedical and health informatics approaches for discovery, application, and analysis related to consumers and patients.

Haldar et al[4] examined patient experiences of undesirable events related to safety and quality of care. Based on a survey of 242 patients and caregivers during a hospital stay, the authors developed a 4-stage conceptual model that reflects patient experiences, from when they first encounter undesirable events, when they could intervene, when visible (eg, pain) and invisible (eg, lack of trust) harms emerge, what types of harms they experience, and what they do in response to harms. They also identified opportunities for informatics solutions related to each stage including "speaking up" risk assessments, apps for navigating invisible harm and reporting options. Their article illustrates how patient-oriented conceptual model development informed discovery of novel targets for informatics interventions.

Huang et al[5] addressed another aspect of safety and quality of care: technically troubled dialysis (TTD) (eg, difference in post-dialysis weight and dry weight was greater than 5%) in a remote monitoring setting. They created a remote monitoring system comprising 3 main components: (a) a mobile application (app) for dialysis patients to input their hemodialysis data (eg, weight, blood pressure, ultra-filtration volumes, blood flows, venous and arterial pressures, session times) as well as notes and emotions, (b) a cloud database for the storage of data, and (3) a web dashboard for healthcare professionals to monitor and send feedback. Notes were processed using sentiment analysis. Subsequently, they assessed the relationship between emoticon use and sentiment and TTD in 156 patients who actively used the app (emoticons, n=122; note, n=146) in 31 159 dialysis sessions of which 13% were classified as TTD. In multi-variate models, both sad emoticons and negative sentiments were significantly associated with higher odds of TTD. This novel approach to capturing emotional status may have utility in predicting longer periods of TTD providing the opportunity for intervention strategies.

Informed by the Integrated Behavior Model, Zhang et al[6] used Twitter to examine determinants (knowledge, attitudes, beliefs) of vaccination behavior related to human papilloma virus (HPV). HPV vaccination is an important strategy in preventing cervical and some other cancers. While HPV vaccination was once recommended only for adolescents, eligibility criteria have been expanded to other vulnerable groups.[7] *Tweets* were classified as either promotional information or consumer discussion prior to application of topic modeling to each set of tweets. Topics were subsequently mapped to the Integrated Behavior Model. Lastly, the authors examined the relationship between the discovered topics in consumer discussions and the responses of HPV-related questions in the Health Information National Trends Survey (HINTS). They found that 112 of the 122 high-quality topics were relevant to consumers' discussions and could be mapped to 6 different Integrated Behavior Model constructs such as (a) "feelings about behavior" (97 topics), (b) "behavioral beliefs" (92 topics), or (b) "normative beliefs—other's behavior" (36 topics). While 45 topics had statistically significant correlations with HINTS responses in terms of geographic distribution, most correlations were modest suggesting that social media-based approaches may complement traditional survey approaches.

To efficiently meet consumer health information needs with reliable sources, Demner-Fushman[8] and her co-authors combined knowledge-based, traditional machine and deep learning approaches to understand consumers' questions and select the best answers from consumer-oriented sources. The end-to-end prototype system is called the Consumer Health Information and Question Answering (ChiQA) system (https://CHiQA.nlm.nih.gov). Sources for evaluating this aspect of CHiQA included simple questions developed for an Alexa pilot test and short and long questions submitted to the National Library of Medicine by consumers. CHiQA achieves 78.7% mean average precision and 87.9% mean reciprocal rank on

simple Alexa questions and 44.5% mean average precision and 51.6% mean reciprocal rank on real-life consumer questions. The findings suggest that the approach works well for simple questions but requires refinement for real-life consumer questions since, among other reasons, there are often multiple subquestions embedded in a single consumer question.

Stonbraker et al[9] iteratively developed and evaluated information visualizations for display of patient-reported symptoms over time. In a 2-phase process, English- or Spanish-speaking target users of the information visualizations completed surveys that included measures of health and graph literacy, visualization preferences, and comprehension. Most had limited health and graph literacy. Almost all (94.3%) of the 35 persons completing the second phase preferred reports with emojis. The highest comprehension scores were for information visualizations with emojis. The percentage of persons who correctly answered all comprehension questions associated with an information visualization that included an emoji alone ranged from 49%–66% and was 69% for an emoji with bar graph suggesting that preference is not necessarily associated with comprehension. While iterative design with the target users was important in refining the information visualizations, the findings highlight the challenges of designing comprehensible longitudinal reports for those with low health and graph literacy.

Continuing the legacy of Warner Slack, the articles highlighted in this editorial illustrate the evolution of informatics solutions to engage the valuable resource of patients and consumers to advance healthcare and self-management activities as well as health outcomes.

## CONFLICT OF INTEREST STATEMENT

None declared.

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