Storytelling as Means of Health Information Sharing in Marginalized Communities

Herman Saksono, Northeastern University, h.saksono@northeastern.edu

First-person storytelling (FPS) is an effective means of health information sharing, especially in marginalized communities [6] that face many barriers to being healthy [9]. Lipsey et al. defined FPS as health narratives told by people "in their own words" [6]. Such narratives can be categorized as informational social support [13] that can help marginalized communities cope with the negative health effects of systemic discrimination leading to health disparities.

Stories are unique as they are a special kind of information and communication [8:53]. For example, when we engage with a story about a single-caregiver mother successfully finding ways to support their children to be healthy, our sensemaking understood the story beyond its mere unfolding of events. Effective stories fit into plotline schemas that we have learned over time [8:69]. In the story above, there is one fitting schema about single-caregiver mothers being impoverished [7]. But another schema did not fit with the schema of poverty: the impoverished mother managed to support their children. However, this is a powerful story that fits into a well-established plotline schema of heroic triumph. Despite the obstacles she faced, the mother was successful in supporting her children's health.

FPS about successes, especially those told by people similar to the audience, can be very effective for health promotion. From the perspective of Social Cognitive Theory [1–3], success stories are essentially *social modeling* — learning new behavior by observing similar peers. Social modeling has been known to enhance self-efficacy, which is a strong predictor of health behavior [12].

My evaluation of the Storywell app underscores the potential of using digitally-mediated FPS to facilitate information sharing and seeking about health behavior [11]. More specifically, physical activity, which is a preventative health behavior that could reduce the risks of chronic and mental health issues [10]. Physical activity is also a health equity issue because being poor is linked to lowered exercise [9].

We designed Storywell to encourage families of low-socioeconomic status neighborhoods to audio-record their stories in being physically active. Then, families can share the story on a digital neighborhood map within Storywell so that other families listen to the story. My in-depth qualitative study demonstrated that community health stories can enhance exercise self-efficacy [11]. More specifically, by vicariously showing that being active is doable using strategies that are relevant to the observer. In other words, social modeling through FPS.

But community FPS is not just for supporting resilience without addressing the origins of disparities. Stories can also cast a spotlight on the root causes of health disparities. These stories call for collective actions. Underscoring that the challenges faced by single-caregiver mothers are linked to income inequities can create two mitigating effects. First, it could lessen the single mothers' psychological burdens from societal stigma by reframing that the obstacles they face were caused by something that is external, stable, and uncontrollable [5]. Second, it enabled impoverished communities to develop a collective identity around health disparities that could spring into long-term collective actions advocating for health equity [4].

With these ideas in mind, I highlight the following questions about using first-person storytelling for future work in health information sharing and seeking in marginalized communities.

1. How can digital tools support community storytelling among marginalized communities, specifically health success stories; while at the same time acknowledging the numerous barriers experienced by the community?
2. How can digital storytelling tools support the development of a collective identity that could lead to effective collective actions without reinforcing traumas?
3. As online communities grow, how can computational tools reduce information overload in health information seeking by matching the observer with mentoring peers? In what ways people can be represented in algorithmic peer-matching tools without oversimplifying and biasing their rich and complex identities?

References

1. Albert Bandura. 1998. Health promotion from the perspective of social cognitive theory. *Psychology and Health*. 13, 4 (1998), 623–649. https://doi.org/10.1080/08870449808407422.

2. Albert Bandura. 1999. Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology*. 2, (1999), 21–41. https://doi.org/10.1111/1467-839X.00024.

3. Albert Bandura. 2001. Social Cognitive Theory of Mass Communication. *Media Psychology*. 3, 3 (2001), 265–299. https://doi.org/10.1207/S1532785XMEP0303_03.

4. Phil Brown, Brian Mayer, Stephen Zavestoski, Theo Luebke, Joshua Mandelbaum, Sabrina McCormick, and Lyson Mercedes. 2017. The Health Politics of Asthma: Environmental Justice and Collective Illness Experience. *Contested Illnesses: Citizens, Science, and Health Social Movements*. P. Brown, R. Morello-Frosch, and S. Zavestoski, eds. https://doi.org/10.1525/california/9780520270206.001.0001.

5. Sandra Graham. 1991. A Review of Attribution Theory in Achievement Contexts. *Educational Psychology Review*. 3, 1 (1991), 5–39. https://doi.org/10.1007/sl0734-011-9486-z.

6. Amanda Faye Lipsey, Amy D. Waterman, Emily H. Wood, and Wendy Balliet. 2020. Evaluation of first-person storytelling on changing health-related attitudes, knowledge, behaviors, and outcomes: A scoping review. *Patient Education and Counseling*. 103, 10 (2020), 1922–1934. https://doi.org/10.1016/j.pec.2020.04.014.

7. Yuan Chiao Lu, Regine Walker, Patrick Richard, and Mustafa Younis. 2020. Inequalities in poverty and income between single mothers and fathers. *International Journal of Environmental Research and Public Health*. 17, 1 (2020). https://doi.org/10.3390/ijerph17010135.

8. Frederick W. Mayer. 2014. *Narrative Politics: Stories and Collective Action*. Oxford University Press.

9. National Center for Health Statistics. 2017. *Health, United States, 2016: With Chartbook on Long-term Trends in Health*. National Center for Health Statistics.

10. Kenneth E. Powell et al. 2019. The scientific foundation for the physical activity guidelines for Americans, 2nd edition. *Journal of Physical Activity and Health*. 16, 1 (2019), 1–11. https://doi.org/10.1123/jpah.2018-0618.

11. Herman Saksono, Carmen Castaneda-Sceppa, Jessica A. Hoffman, Vivien Morris, Magy Seif El-Nasr, and Andrea G. Parker. 2021. StoryMap: Using Social Modeling and Self-Modeling to Support Physical Activity Among Families of Low-SES Backgrounds. In *CHI Conference on Human Factors in Computing Systems (CHI '21)*, May 2021, Yokohama, Japan, 14 pages. https://doi.org/10.1145/3411764.3445087.

12. V. J. Strecher, B. M. DeVellis, M. H. Becker, and I. M. Rosenstock. 1986. The role of self-efficacy in achieving health behavior change. *Health Education Quarterly*. 13, 1 (1986), 73–92. https://doi.org/10.1177/109019818601300108.

13. Bert N. Uchino. 2014. Social Support and Physical Health. *Social Support and Physical Health*. 1–15. https://doi.org/10.12987/yale/9780300102185.001.0001.