

Narratives and Stories: Novel Approaches to Improving Patient-Facing Information Resources and Patient Engagement

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Abstract. Patient-centered healthcare requires development of materials for health consumers that increase health literacy, enrich the provider-patient dialog, empower shared decision-making, and improve downstream outcomes. Unfortunately, evidence suggests current methods of communication, including print and electronic media, are inadequate. The Narrative Theory of Learning is grounded in the premise that humans define their experiences and form cognitive structures (e.g., new learning, novel concepts) within the context of narratives. Simply put, humans remember stories better than fragmented bits of information. Therefore, we propose leveraging the power of narratives and stories to improve the efficacy and impact of consumer health applications. We describe several examples of future technologies that could incorporate narrative techniques and present a call to action for future research and development.

Keywords. Usability engineering, implementation science, consumer informatics, health information technology, quality improvement, health literacy

1. Background

High quality healthcare is contingent upon meaningful engagement of patients in all aspects of their care including information-seeking, clarification of goals, and shared decision-making [1]. Moving to patient-centered models of care frequently requires the implementation of evidence-based “bundles” – processes and tools that foster dialog, improve patient self-management, and downstream clinical outcomes [2]. Bundle elements may include (1) re-imagined workflows; (2) educational artifacts (e.g., drug handouts, illness management brochures, clinic visit summaries); and (3) consumer-facing health information technologies (HIT) [3].

2. Problem Statement

Traditional methods of communication intended to educate and engage patients are often inadequate [4]. Studies suggest that up to 80% of information provided to patients is

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immediately forgotten [5]. Further, in over 50% of encounters, patients or representatives do not understand the diagnosis or treatment plan, and only 12% of patients proficiently act upon health information [6, 7]. For example, materials accompanying prescription medications and intended to improve medication safety (e.g., paper package inserts, medication guides, consumer medication information) are often confusing to health consumers (e.g., patients, families, caregivers) [8]. Moreover, even when printed materials (e.g., tests, results, management recommendations, or side effects) are furnished in consumer-friendly language, patients may need additional context, such as prior experiences or examples, to make values-based decisions [9, 10].

Technologies intended to close these communication gaps and improve patient self-efficacy (e.g., patient portals, self-service kiosks, and mobile applications) can paradoxically increase cognitive overhead, particularly in patients with low health or information technology literacy [11, 12]. Hence, while there is a role for user experience (UX) research to inform the human factors of responsive designs, we also believe developers need to consider approaches that borrow from other industries such as education, business, and the social and psychological sciences [13]. In this monograph, we propose leveraging the power of narratives and storytelling to improve the impact of consumer health information systems.

3. Purpose and Audience

In the following sections, we (1) discuss key references supporting the value of multi-channel learning; (2) review an established model of learning that uses narrative techniques; (3) offer hypothetical examples of tools using stories and narratives; and (4) present suggestions for future research and development. This paper should be of interest to researchers in health informatics and the social sciences as well as health services researchers engaged in “boots-on-the-ground” implementation and dissemination work.

4. Key Literature

Mayer’s Cognitive Theory of Multimedia Learning argues that presenting information using multiple channels (e.g., auditory and visual) can improve cognitive performance [14]. The theory describes several evidence-based principles to guide development of instructional content such as using photographs, graphs, timelines, and infographics to communicate information [14-17]. Unfortunately, clinical resources using these strategies have an unreliable effect upon patient recall, accuracy, and self-efficacy [5, 7, 18]. Rather than simply combining channels (e.g., audio and visual), instructional materials should mirror the way the human mind works by organizing information logically and sequentially. Studies suggest using interactive content can improve patient understanding of clinical material and clear narratives can foster insights to inform patient-centered and values-based decision making [10, 19-21].

UX researchers have also begun testing consumer health information systems that attempt to empower patients and enrich the clinical dialog [22, 23]. However, design strategies are still lacking [12, 24]. For example, the inclusion of pharmaceutical images in an application for medication reconciliation neither improved patient accuracy, nor the ability to detect adherence discrepancies [25].

To summarize, currently there is no single most effective method to communicate

health information to consumers. Moreover, learning theories proven in other domains do not reliably translate to successful consumer informatics software. While these theories hold promise for the development of new applications, additional research is needed to understand how context mediates learning (e.g., mode of communication, types of information conveyed, and patient-specific characteristics). Moreover, we believe that the use of narratives and stories warrants exploration. It is possible that narratives can organize health information for patients to improve comprehension, recall, and application in values-based decision-making.

5. Theoretical Model for Narrative Learning

Cognitive scientists, psychologists, and anthropologists have long acknowledged the human tendency to draw associations of causation between observations [21, 26, 27]. Presumably, these heuristics conferred an evolutionary advantage, enabling individuals to adapt to unfamiliar environments and respond quickly in critical situations [28]. With regards to andragogy, constructivist theory and the related contextual model of learning argue that humans pragmatically encode information through lenses of personal history, socio-cultural environment, and physical space [29, 30]. Learning is deeply embedded in context and enriched through reflection that occurs over time [31].

Bruner's discovery learning theory, though constructivist by nature, goes further by arguing that narrative thinking is the "default mode" for constructing meaning [29, 32, 33]. Clark and others have built on this foundation and advanced the narrative theory of learning as an epistemological tool for engaging learners on a deeply emotional and personal level (Table 1) [30]. Stories are not only cognitive scaffolds to consolidate learning, but also recognizable paths to personal agency within a larger fabric of cultural norms and sociotechnical systems [30, 32, 34]. Learners that can link a concept to their own experiences can also construct a counter narrative to increase self-efficacy and influence social systems. For this reason, Avraamidou and colleagues describe the use of stories to teach sophisticated scientific concepts [29, 35].

Table 1. The essential components of a narrative, adapted from Avraamidou [35] with an example adapted from Dohan [10].

Component	Description	Example
Purpose	To help understand the natural and human world.	Why a patient with early stage breast cancer opted for bilateral mastectomy and reconstruction.
Events	A sequence of connected events.	An exchange with a breast cancer survivor influenced her decision.
Structure	An identifiable beginning, middle, and end.	She learned about treatments, listened to another patient's perspective, and saw an opportunity.
Time	Narratives concern the past.	A prior exchange created new insights beyond the recommendations from a surgeon.
Agency	Actors cause and experience events.	The story aligned with the patient's feelings about identity, sexuality, and empowerment.
Narrator	The teller can be a character or an observer.	A breast cancer survivor provided the account.
Reader	The listener must be able to recognize and interpret.	A patient weighing options used the narrative to consider alternative decisions and outcomes.

6. Practical Strategies Using Narratives and Emerging Technologies

We propose several approaches in which the narrative theory of learning may inform HIT development, health systems delivery, and patient-centered care. We categorize

these approaches into:

- (a) **Interpersonal communication.** Practitioners should deliver important messages and educational content through established case stories (e.g., description of drug interactions, symptom manifestations) with an identifiable narrator and sequence of events [36]. Practical ways to scale stories for clinical settings include using standardized interview scripts during interviews and patient learning journals to track understanding over time [30]. Also, conducting group medical appointments where peers can recount personal experiences and insights has been shown to be an effective way to provide hope, support, and disease management strategies [37].
- (b) **Distributed networks.** Peer-networks, on-line rating platforms, and social media are powerful channels for exchanging information, identifying solutions, and fostering supportive communities [12, 38]. For example, Henao and colleagues describe Alicanto (<http://alicantocloud.com>), a multi-function social community website dedicated to maternal and fetal health that includes educational materials, a discussion forum, and toolkits to improve self-management [39]. We envision virtual hubs providing a repository of searchable healthcare-related stories from patient narrators and aggregated patient-centered experiences [38].
- (c) **Educational artifacts.** Content providers should organize educational materials using stories that describe an inpatient care-day or clinic encounter, as well as the purpose, key events, clinical reasoning, and potential health outcomes patients may anticipate. In the future, providers may forgo traditional print media such as after-clinic summaries, drug monographs, and disease brochures in favor of narrative media such as internet web logs (i.e., “blogs”), podcasts, and videos [19].
- (d) **Human-computer interfaces.** Current consumer health interfaces are still in their relative infancy and often suffer from usability issues [12]. Future interfaces may draw heavily from the gaming industry—particularly role-playing and immersive formats – by using devices and affordances that place the user at the center of interactive or enhanced experiences. For example, augmented reality may help patients experience real-world scenarios such as advanced directives discussions, hospital navigation, and specialty consultation [40].

7. Implications for Future Research and Call to Action

In summary, we believe that the narrative theory of learning offers a new direction for health services research, informatics development, and implementation campaigns. Rather than being orthogonal to current development efforts, it offers a theoretical scaffolding to inform new concepts and a roadmap for interdisciplinary research. We propose three practical strategies to foster the inclusion of narrative theory into research protocols, user-centered design, and care delivery:

- (a) **Intersectional research.** We believe the wellspring of innovation and research breakthroughs are dependent upon collaboration between disparate disciplines such as healthcare, information technology, business, and the social sciences.

Future initiatives should strive to include stakeholders that bring fresh perspectives to the design of human-centered products and contextually-sensitive research protocols. Specialists in UX, design, education, philosophy, anthropology, cognitive psychology, public health, business, and marketing have important roles to play in these initiatives.

- (b) **UX methods.** The software and technology design lifecycle must include UX methods at every stage. We envision including UX techniques at the requirements definition, design prototyping, and implementation phases. At each step, researchers should seek to clarify user values, environmental constraints, and informational needs through ethnography, workflow mapping, journey mapping, and empathy mapping [41]. Design activities should include high-fidelity simulations to validate use-cases and surface practical user needs [42]. Data collected through these activities will help to inform more robust use-cases, educational environments, and responsive interface designs.
- (c) **Implementation bundles.** We envision future implementation and dissemination campaigns that include story-driven patient artifacts and HIT-supported communities of practice. To properly design, deploy, and evaluate tool effectiveness, it is critical that protocols include theoretical frameworks informed by narrative learning theory. Also, measurement instruments should seek to quantify the relationship and impact of narratives upon consumer learning, health literacy demands, and disease self-management [7].

8. Conclusions

Consumer health information systems are becoming increasingly prevalent. However, at present these systems are failing to capitalize on what we know to be true about human cognition: we are better at remembering stories and narratives than discrete bits of disconnected information. Developers need research to understand and capitalize upon the potential benefits of integrating narratives into consumer health information.

References

- [1] Improving Outcomes Important to Patients, Patient Centered Outcomes Research Institute (PCORI), (2019). <https://www.pcori.org/> (accessed May 16, 2019).
- [2] What is patient-centered care?, NEJM Catal. (2017). <https://catalyst.nejm.org/what-is-patient-centered-care/> (accessed May 16, 2019).
- [3] S.S. Ono, B.F. Crabtree, J.R. Hemler, B.A. Balasubramanian, S.T. Edwards, L.A. Green? et al., Taking innovation to scale in primary care practices: the functions of health care extension, *Health Affairs* **37** (2018), 222-230.
- [4] D.M. McCarthy, K.R. Waite, L.M. Curtis, K.G. Engel, D.W. Baker, and M.S. Wolf, What did the doctor say? Health literacy and recall of medical instructions, *Med Care* **50** (2012), 277.
- [5] R.P. Kessels, Patient's memory of medical information. *J of Royal Society of Med* **96** (2003), 219-222.
- [6] E. Azoulay, S. Chevret, G. Leleu, F. Pochard, L. Barboteu, et al., Half the families of intensive care unit patients experience inadequate communication with physicians, *Crit Care Med* **28** (2000), 3044-3049.
- [7] H. Koh, C. Brach, L. Harris, and M. Parchman, A proposed 'Health Literate Care Model' would constitute a systems approach to improving patients' engagement in care, *Health Affairs* **32** (2013), 357-367.
- [8] S. Shiffman, K.K. Gerlach, M.A. Semboer, J.M. Rohay, Consumer understanding of prescription drug information: an illustration using an antidepressant medication, *Ann Pharmacother* **45** (2011), 452-458.
- [9] P.C. Tang and C. Newcomb, Informing patients: a guide for providing patient health information. *J Am Med Inform Assoc* **5** (1998), 563-70.

- [10] D. Dohan, S.B. Garrett, K.A. Rendle, M. Halley, and C. Abramson, The importance of integrating narrative into health care decision making, *Health Affairs* **4** (2016), 720-725.
- [11] H. Monkman and A. Kushniruk, The Consumer Health Information System Adoption Model, *Stud Health Technol Inform* **218** (1995), 218-231.
- [12] G. Demiris, Consumer health informatics: Past, present, and future of a rapidly evolving domain, *Yearbook of Medical Informatics* **25** (2016), S42-S7.
- [13] S. Mullangi, A.M. Ibrahim, and V. Chopra, Toward Patient-Centered Hospital Design: What Can Airports Teach Us?, *Ann Intern Med* **167** (2017), 48-49.
- [14] R.E. Mayer, Cognitive Theory of Multimedia Learning, in: R. Mayer (Ed.), *Camb. Handb. Multimed. Learn.*, Cambridge University Press, Cambridge, 2014, 43-71.
- [15] P. Knapp, D.K. Raynor, A.H. Jebar, and S.J. Price. Interpretation of medication pictograms by adults in the UK, *Ann Pharmacother* **39** (2005), 1227-1233.
- [16] R. Moreno and R. Mayer, Interactive multimodal learning environments, *Educ Psychol Rev* **19** (2007), 309-326.
- [17] Q. Zeng-Treitler, S. Perri, C. Nakamura, J. Kuang, B. Hill, D.A.A. Bui, et al., Evaluation of a pictograph enhancement system for patient instruction: a recall study, *J Am Med Inform Assoc* **21** (2014), 1026-1031.
- [18] M.G. Katz, S. Kripalani, and B.D. Weiss, Use of pictorial aids in medication instructions: a review of the literature, *Am J Health Syst Pharm*. **63** (2006), 2391-2397.
- [19] L. Ricciardi, F. Mostashari, J. Murphy, J. Daniel, and E. Siminerio, A national action plan to support consumer engagement via e-health, *Health Affairs* **32** (2013), 376-384.
- [20] J. McDonough, Using and misusing anecdote in policy making, *Health Affairs* **20** (2001), 207-212.
- [21] J. Gottschall, *The Storytelling Animal: How Stories Make Us Human*, Houghton Mifflin Harcourt, Boston, Massachusetts, 2012.
- [22] L. Heyworth, A.M. Paquin J. Clark, V. Kamenker, M. Stewart, T. Martin, et al., Engaging patients in medication reconciliation via a patient portal following hospital discharge, *J Am Med Inform Assoc* **21** (2013), e157-e62.
- [23] A.N. Cohen, M.J. Chinman, A.B. Hamilton, F. Whelan, and A.S. Young, Using patient-facing kiosks to support quality improvement at mental health clinics, *Med Care* **51** (2013), S13-20.
- [24] D.A. Haggstrom, J.J. Saleem, A.L. Russ, J. Jones, S.A. Russell, and N.R. Chumbler, Lessons learned from usability testing of the VA's personal health record, *J Am Med Inform Assoc* **18** (2011), i13-7.
- [25] B.J. Lesselroth, K. Adams, V.L. Church, S. Tallett, Y. Russ, J. Wiedrick, et al., Evaluation of Multimedia Medication Reconciliation Software: A Randomized Controlled, Single-Blind Trial to Measure Diagnostic Accuracy for Discrepancy Detection, *Appl Clin Inform* **9** (2018), 285-301.
- [26] G.A. Klein, *Sources of power: How people make decisions*, MIT press, Cambridge, Massachusetts, 2017.
- [27] D. Kahneman and P. Egan, *Thinking, fast and slow*, Farrar, Straus and Giroux, New York, 2011.
- [28] G. Gigerenzer, *Gut feelings: The intelligence of the unconscious*, Penguin, 2007.
- [29] M. Murmann and L. Avraamidou, Narrative as a learning tool in science centers: potentials, possibilities and merits. *Sci Commun* **13** (2014), A02.
- [30] M.C. Clark and M. Rossiter, Narrative learning in adulthood, *New Directions for Adult Continuing Education* **119** (2008), 61-70.
- [31] J. Falk and L. Dierking, The 95 percent solution, *American Scientist* **98** (2010), 486-493.
- [32] J. Bruner, The narrative construction of reality, *Journal of Critical Inquiry* 1991;18(1):1-21.
- [33] J. Foer, *Moonwalking with Einstein: The art and science of remembering everything*, Penguin, 2012.
- [34] I.F. Goodson, G. Biesta, M. Tedder, and N. Adair, *Narrative learning*, Routledge, 2010.
- [35] L. Avraamidou, J. Osborne, The role of narrative in communicating science, *Int J Sci Educ* **31** (2009), 1683-1707.
- [36] A.M. Tomey, Learning with cases, *J Contin Educ Nurs* **34** (2003), 34-38.
- [37] K. Ramdas, A. Darzi, Adopting innovations in care delivery - the case of shared medical appointments, *N Engl J Med* **376** (2017), 1105-1107.
- [38] B. Ranard, R. Werner, T. Antanavicius, A. Schwartz, R.J. Smith, Z. Meisel, et al., Yelp reviews of hospital care can supplement and inform traditional surveys of the patient experience of care, *Health Affairs* **35** (2016), 697-705.
- [39] J. Henao, Y. Quintana, and C. Safran, An informatics framework for maternal and child health (MCH) monitoring, *Stud Health Technol Inform* **257** (2019), 157-162.
- [40] The 10 Most Exciting Digital Health Stories of 2017 - The Medical Futurist, (n.d.). <https://medicalfuturist.com/10-exciting-digital-health-stories-2017> (accessed May 16, 2019).
- [41] H. Loranger, P. Laubheimer, and J. Nielsen, *Effective Agile UX Product Development*, Nielsen Norman Group, Fremont, California, 2012.
- [42] E. Borycki and A. Kushniruk, Towards an integrative cognitive-socio-technical approach in health informatics: analyzing technology-induced error involving health information systems to improve patient safety, *Open Med Inform J* **4** (2010), 181.