



## Meghan Halley

Assistant Professor (Research) of Pediatrics (Stanford Center for Biomedical Ethics)

Pediatrics - Center for Biomedical Ethics

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#### BIO

Meghan Halley, PhD, MPH is Assistant Professor of Pediatrics (Research) in the Center for Biomedical Ethics at Stanford University School of Medicine. With training in medical anthropology, public health and health services research, her scholarship draws on multidisciplinary theoretical and methodological approaches to examine ethical, legal, social and policy questions arising in clinical and translational research. Her areas of expertise include the ethics of new genomic technologies, normative frameworks for integrating research and clinical care, challenges and opportunities in patient and community engagement, and the epistemic and ethical implications of valuing new health interventions. Her work has been funded by the National Institutes of Health, the Patient Centered Outcomes Research Institute, and the National Science Foundation and published in high-impact journals including the New England Journal of Medicine, Nature Genetics, and the American Journal of Bioethics.

#### ACADEMIC APPOINTMENTS

- Assistant Professor (Research), Pediatrics - Center for Biomedical Ethics
- Member, Maternal & Child Health Research Institute (MCHRI)

#### PROFESSIONAL EDUCATION

- PhD, Case Western Reserve University , Anthropology (2012)
- MPH, Case Western Reserve University , Public Health (2009)
- BA, University of Wisconsin-Madison , Anthropology (2005)

#### SERVICE, VOLUNTEER, AND COMMUNITY WORK

- Co-Chair, Patient Education and Empowerment Resource (January 1, 2021 - 12/31/2022)
- Member, Board of Directors (11/1/2021)

### Publications

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#### PUBLICATIONS

- **Whose Values Define Value? Procedural Justice and the Personal Utility of Clinical Genomic Testing.** *The American journal of bioethics : AJOB*  
Halley, M. C.  
2026; 26 (5): 1-3
- **"Nobody listened to us for years": Parents' experiences of provider communication in the diagnostic odyssey.** *Molecular genetics and metabolism*  
Nguyen, M. M., Mahfoozi, S., Bonner, D., Martschenko, D. O., Giri, A., Tang, C., Bernstein, J. A., Wheeler, M. T., Halley, M. C.  
2025; 146 (4): 109283

- **Stanford Center for Undiagnosed Diseases: a decade of advancing genetic diagnosis and discovery**  
Bonner, D., Carter, J., Reuter, C., Marwaha, S., Kravets, E., Hom, J., Sampson, J., Fisher, P., Ashley, E., Tabor, H., Halley, M., Wheeler, M., Bernstein, et al  
SPRINGER NATURE.2025: 877
- **According to Which Criteria Should the Undiagnosed Diseases Network's Value Be Assessed?** *AMA journal of ethics*  
Halley, M., Tabor, H.  
2025; 27 (10): E750-755
- **Health Related Quality of Life for Rare Disease Caregivers**  
Lin, C., Halley, M. C., Lavelle, T. A.  
SAGE PUBLICATIONS INC.2025
- **Developing Therapeutics for Rare Cardiovascular Diseases.** *American heart journal*  
Lerman, J. B., Koeberl, D. D., Epstein, S., Roessig, L., Stan, R., Halley, M., Owens, A. T., Greenberg, B., Alexander, K. M., Day, S. M., Maurer, M. S., Adler, E. D., Hernandez, et al  
2025
- **Sustainability in translational genomics research with undiagnosed patients: What is it, why do we need it, and how do we do it?** *Genetics in medicine : official journal of the American College of Medical Genetics*  
Young, J. L., Tang, C., Liang, L., Ashley, E., Tabor, H. K., Halley, M. C.  
2025: 101458
- **Exploring how claims of 'suffering' are operationalized in pediatric critical care.** *Journal of pain and symptom management*  
Grekov, K., Batten, J., Tate, T., Anand, K. J., Magnus, D., Halley, M. C.  
2025
- **"Learning from those who know the system inside and out": Experiences of physician mothers who are informal caregivers.** *Families, systems & health : the journal of collaborative family healthcare*  
Semere, W., Ponce, A. N., Linos, E., Jagsi, R., Mangurian, C., Halley, M. C.  
2024
- **Telehealth Is Effective in the Evaluation of Individuals With Undiagnosed Rare Disorders: An Undiagnosed Diseases Network Study.** *American journal of medical genetics. Part A*  
Tan, Q. K., McConkie-Rosell, A., Mahoney, R., Spillmann, R. C., Schoch, K., Chanprasert, S., Acosta, M. T., Toro, C., Rosenfeld, J. A., Orengo, J. P., Scott, D. A., Granadillo, J. L., Sisco, et al  
2024: e63956
- **Health-related quality of life in patients with diverse rare diseases: An online survey.** *Genetics in medicine open*  
Rao, A., Yabumoto, M., Ward-Lev, E., Miller, E. G., Naik, H., Halley, M. C.  
2024; 2: 101889
- **Increasing Diversity, Equity, Inclusion, and Accessibility in Rare Disease Clinical Trials.** *Pharmaceutical medicine*  
Baynam, G., Baker, S., Steward, C., Summar, M., Halley, M., Pariser, A.  
2024
- **The Undiagnosed Diseases Network: Characteristics of solvable applicants and diagnostic suggestions for non-accepted ones.** *Genetics in medicine : official journal of the American College of Medical Genetics*  
Mulvihill, J. J., Findley, L., Ni, W., Sinsheimer, J. S., Cole, F. S., Esteves, C., Bernstein, J. A., Newman, J. H., Wheeler, M. T., Mokry, J. R.  
2024: 101203
- **Career flexibility for PAs: What makes switching specialties successful?** *JAAPA : official journal of the American Academy of Physician Assistants*  
Ward-Lev, E., Kuriakose, C., Navoa, J. J., Halley, M.  
2024
- **Moral Engagement and Disengagement in Health Care AI Development.** *AJOB empirical bioethics*  
Nichol, A. A., Halley, M., Federico, C., Cho, M. K., Sankar, P. L.  
2024: 1-10

- **Practical Approaches to Enhancing Fairness, Social Responsibility and the Inclusion of Diverse Viewpoints in Biomedicine.** *Pacific Symposium on Biocomputing. Pacific Symposium on Biocomputing*  
Martschenko, D. O., Martinez-Martin, N., Halley, M.  
2024; 29: 645-649
- **Not in my AI: Moral engagement and disengagement in health care AI development.** *Pacific Symposium on Biocomputing. Pacific Symposium on Biocomputing*  
Nichol, A. A., Halley, M. C., Federico, C. A., Cho, M. K., Sankar, P. L.  
2023; 28: 496-506
- **Developer Perspectives on Potential Harms of Machine Learning Predictive Analytics in Health Care: Qualitative Analysis.** *Journal of medical Internet research*  
Nichol, A. A., Sankar, P. L., Halley, M. C., Federico, C. A., Cho, M. K.  
2023; 25: e47609
- **Genomics Research with Undiagnosed Children: Ethical Challenges at the Boundaries of Research and Clinical Care** *JOURNAL OF PEDIATRICS*  
Halley, M. C., Young, J. L., Tang, C., Mintz, K. T., Lucas-Griffin, S., Maghiro, A., Ashley, E. A., Tabor, H. K., Undiagnosed Diseases Network  
2023; 261
- **Blurred Boundaries: Toward an Expanded Ethics of Research and Clinical Care.** *The American journal of bioethics : AJOB*  
Halley, M. C., Olson, N. W.  
2023; 23 (8): 5-9
- **Rare Disease, Advocacy and Justice: Intersecting Disparities in Research and Clinical Care.** *The American journal of bioethics : AJOB*  
Halley, M. C., Halverson, C. M., Tabor, H. K., Goldenberg, A. J.  
2023: 1-10
- **Demographic Characteristics Associated With Perceptions of Personal Utility in Genetic and Genomic Testing: A Systematic Review.** *JAMA network open*  
Miller, E. G., Young, J. L., Rao, A., Ward-Lev, E., Halley, M. C.  
2023; 6 (5): e2310367
- **Participation in a national diagnostic research study: assessing the patient experience.** *Orphanet journal of rare diseases*  
Rosenfeld, L. E., LeBlanc, K., Nagy, A., Ego, B. K., Undiagnosed Diseases Network, McCray, A. T., Acosta, M. T., Adam, M., Adams, D. R., Alvarez, R. L., Alvey, J., Amendola, L., Andrews, A., et al  
2023; 18 (1): 73
- **Patient Perspectives of Health System Barriers to Accessing Care for Hidradenitis Suppurativa: A Qualitative Study.** *JAMA dermatology*  
Barnes, L. A., Shukla, N., Paul, M., de Vere Hunt, I., Halley, M. C., Linos, E., Naik, H. B.  
2023
- **Formally comparing topic models and human-generated qualitative coding of physician mothers' experiences of workplace discrimination** *BIG DATA & SOCIETY*  
Miner, A. S., Stewart, S. A., Halley, M. C., Nelson, L. K., Linos, E.  
2023; 10 (1)
- **What is "Personal" About Personal Experience? A Call to Reflexivity for All.** *The American journal of bioethics : AJOB*  
Halverson, C., Halley, M.  
2023; 23 (1): 39-41
- **Perspectives of Rare Disease Social Media Group Participants on Engaging With Genetic Counselors: Mixed Methods Study.** *Journal of medical Internet research*  
Yabumoto, M., Miller, E., Rao, A., Tabor, H. K., Ormond, K. E., Halley, M. C.  
2022; 24 (12): e42084
- **Beyond "Ensuring Understanding": Toward a Patient-Partnered Neuroethics of Brain Device Research.** *AJOB neuroscience*  
Halley, M. C., Dixon-Salazar, T., Wexler, A.  
2022; 13 (4): 241-244
- **Supporting undiagnosed participants when clinical genomics studies end.** *Nature genetics*

Halley, M. C., Ashley, E. A., Tabor, H. K.  
2022

- **Impact of Sexual Harassment and Social Support on Burnout in Physician Mothers.** *Journal of women's health (2002)*  
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2022
- **A call for an integrated approach to improve efficiency, equity and sustainability in rare disease research in the United States.** *Nature genetics*  
Halley, M. C., Smith, H. S., Ashley, E. A., Goldenberg, A. J., Tabor, H. K.  
2022
- **A qualitative exploration of the experiences of itch for adults living with epidermolysis bullosa.** *The British journal of dermatology*  
de Vere Hunt, I., Halley, M., Sum, K., Yekrang, K., Phung, M., Good, J., Linos, E., Chiou, A. S.  
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- **Perceived utility and disutility of genomic sequencing for pediatric patients: Perspectives from parents with diverse sociodemographic characteristics.** *American journal of medical genetics. Part A*  
Halley, M. C., Young, J. L., Fernandez, L., Kohler, J. N., Undiagnosed Diseases Network, Bernstein, J. A., Wheeler, M. T., Tabor, H. K.  
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- **Beyond race: Recruitment of diverse participants in clinical genomics research for rare disease.** *Frontiers in genetics*  
Young, J. L., Halley, M. C., Anguiano, B., Fernandez, L., Bernstein, J. A., Wheeler, M. T., Tabor, H. K., Undiagnosed Diseases Network Consortium  
2022; 13: 949422
- **From "Ought" to "Is": Surfacing Values in Patient and Family Advocacy in Rare Diseases.** *The American journal of bioethics : AJOB*  
Halley, M. C.  
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- **Opportunities and pitfalls of social media research in rare genetic diseases: a systematic review.** *Genetics in medicine : official journal of the American College of Medical Genetics*  
Miller, E. G., Woodward, A. L., Flinchum, G., Young, J. L., Tabor, H. K., Halley, M. C.  
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- **Barriers and facilitators to mobile health and active surveillance use among older adults with skin disease.** *Health expectations : an international journal of public participation in health care and health policy*  
Johnson, A., Shukla, N., Halley, M., Nava, V., Budaraju, J., Zhang, L., Linos, E.  
2021
- **A Typology of Existing Machine Learning-Based Predictive Analytic Tools Focused on Reducing Costs and Improving Quality in Health Care: Systematic Search and Content Analysis.** *Journal of medical Internet research*  
Nichol, A. A., Batten, J. N., Halley, M. C., Axelrod, J. K., Sankar, P. L., Cho, M. K.  
2021; 23 (6): e26391
- **"Doctors can read about it, they can know about it, but they've never lived with it": How parents use social media throughout the diagnostic odyssey.** *Journal of genetic counseling*  
Deutch, N. T., Beckman, E., Halley, M. C., Young, J. L., Reuter, C. M., Kohler, J., Bernstein, J. A., Wheeler, M. T., Undiagnosed Diseases Network, Ormond, K. E., Tabor, H. K.  
2021
- **Age-Related Differences in Experiences with Social Distancing at the Onset of the COVID-19 Pandemic: A Computational and Content Analytic Investigation of Natural Language.** *JMIR human factors*  
Moore, R. C., Lee, A. Y., Hancock, J. T., Halley, M. C., Linos, E.  
2021
- **"It seems like COVID-19 now is the only disease present on Earth": living with a rare or undiagnosed disease during the COVID-19 pandemic.** *Genetics in medicine : official journal of the American College of Medical Genetics*  
Halley, M. C., Stanley, T. n., Maturi, J. n., Goldenberg, A. J., Bernstein, J. A., Wheeler, M. T., Tabor, H. K.  
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- **The Intersection of Work and Home Challenges Faced by Physician Mothers During the Coronavirus Disease 2019 Pandemic: A Mixed-Methods Analysis.** *Journal of women's health (2002)*

- Halley, M. C., Mathews, K. S., Diamond, L. C., Linos, E. n., Sarkar, U. n., Mangurian, C. n., Sabry, H. n., Goyal, M. K., Olazo, K. n., Miller, E. G., Jagsi, R. n., Linos, E. n.  
2021
- **Anxiety Levels Among Physician Mothers During the COVID-19 Pandemic.** *The American journal of psychiatry*  
Linoss, E., Halley, M. C., Sarkar, U., Mangurian, C., Sabry, H., Olazo, K., Mathews, K. S., Diamond, L., Goyal, M. K., Linos, E., Jagsi, R.  
2021; 178 (2): 203–4
  - **Caring for the Caregivers - Covid-19 Vaccination for Essential Members of the Health Care Team.** *The New England journal of medicine*  
Halley, M. C., Mangurian, C. n.  
2021
  - **When All You Have Is Quality of Life - Making Medical Decisions in the Face of Uncertainty.** *The New England journal of medicine*  
Halley, M. C.  
2020; 383 (16): 1507–9
  - **Barriers and Facilitators to Real-world Implementation of the Diabetes Prevention Program in Large Healthcare Systems: Lifestyle Coach Perspectives.** *Journal of general internal medicine*  
Halley, M. C., Petersen, J., Nasrallah, C., Szwernski, N., Romanelli, R., Azar, K. M.  
2020
  - **Differing views regarding diet and physical activity: adolescents versus parents' perspectives.** *BMC pediatrics*  
Azar, K. M., Halley, M., Lv, N., Wulfovich, S., Gillespie, K., Liang, L., Goldman Rosas, L.  
2020; 20 (1): 137
  - **Association between financial links to indoor tanning industry and conclusions of published studies on indoor tanning: systematic review.** *BMJ (Clinical research ed.)*  
Adekunle, L., Chen, R., Morrison, L., Halley, M., Eng, V., Hendlin, Y., Wehner, M. R., Chren, M., Linos, E.  
2020; 368: m7
  - **Development of a patient decision aid for the management of superficial basal cell carcinoma (BCC) in adults with a limited life expectancy.** *BMC medical informatics and decision making*  
Junn, A. n., Shukla, N. R., Morrison, L. n., Halley, M. n., Chren, M. M., Walter, L. C., Frosch, D. L., Matlock, D. n., Torres, J. S., Linos, E. n.  
2020; 20 (1): 81
  - **Identifying barriers to care and research in hidradenitis suppurativa: findings from a patient engagement event.** *The British journal of dermatology*  
Shukla, N., Paul, M., Halley, M., Lowes, M. A., Hester, V., Aguilar, C., Guilbault, S., Long, T. S., Taylor, A., Thompson, A. C., Yannuzzi, C. A., Linos, E., Naik, et al  
2019
  - **Implementation of a group-based diabetes prevention program within a healthcare delivery system.** *BMC health services research*  
Azar, K. M., Nasrallah, C., Szwernski, N. K., Petersen, J. J., Halley, M. C., Greenwood, D., Romanelli, R. J.  
2019; 19 (1): 694
  - **Beyond exploratory: a tailored framework for designing and assessing qualitative health research.** *BMJ open*  
Rendle, K. A., Abramson, C. M., Garrett, S. B., Halley, M. C., Dohan, D.  
2019; 9 (8): e030123
  - **Motivations among sexual-minority men for starting and stopping indoor tanning.** *The British journal of dermatology*  
Admassu, N., Pimentel, M. A., Halley, M. C., Torres, J., Pascua, N., Katz, K. A., Linos, E.  
2019; 180 (6): 1529-1530
  - **Supporting caregivers during hematopoietic cell transplantation for children with primary immunodeficiency disorders** *JOURNAL OF ALLERGY AND CLINICAL IMMUNOLOGY*  
Yoo, J., Halley, M. C., Lown, E., Yank, V., Ort, K., Cowan, M. J., Dorsey, M. J., Smith, H., Lyengar, S., Scalchunes, C., Mangurian, C.  
2019; 143 (6): 2271–78
  - **Physician mothers' experience of workplace discrimination: a qualitative analysis** *BMJ-BRITISH MEDICAL JOURNAL*  
Halley, M. C., Rustagi, A. S., Torres, J. S., Linos, E., Plaut, V., Mangurian, C., Choo, E., Linos, E.  
2018; 363: k4926

- **Beyond Consent: Building Trusting Relationships With Diverse Populations in Precision Medicine Research** *AMERICAN JOURNAL OF BIOETHICS*  
Kraft, S. A., Cho, M. K., Gillespie, K., Halley, M., Varsava, N., Ormond, K. E., Luft, H. S., Wilfond, B. S., Lee, S.  
2018; 18 (4): 3–20
- **Collecting Practice-level Data in a Changing Physician Office-based Ambulatory Care Environment: A Pilot Study Examining the Physician induction interview Component of the National Ambulatory Medical Care Survey.** *Vital and health statistics. Series 2, Data evaluation and methods research*  
Halley, M. C., Rendle, K. A., Gugerty, B., Lau, D. T., Luft, H. S., Gillespie, K. A.  
2017: 1-18
- **Mapping the Decision-Making Process for Adjuvant Endocrine Therapy for Breast Cancer: The Role of Decisional Resolve** *MEDICAL DECISION MAKING*  
Beryl, L. L., Rendle, K. A. S., Halley, M. C., Gillespie, K. A., May, S. G., Glover, J., Yu, P., Chattopadhyay, R., Frosch, D. L.  
2017; 37 (1): 79–90
- **The Importance Of Integrating Narrative Into Health Care Decision Making.** *Health affairs (Project Hope)*  
Dohan, D., Garrett, S. B., Rendle, K. A., Halley, M., Abramson, C.  
2016; 35 (4): 720-5
- **An exploratory mixed-methods crossover study comparing DVD- vs. Web-based patient decision support in three conditions: The importance of patient perspectives** *HEALTH EXPECTATIONS*  
Halley, M. C., Rendle, K. A. S., Gillespie, K. A., Stanley, K. M., Frosch, D. L.  
2015; 18 (6): 2880–91
- **Implementation of Patient Decision Support Interventions in Primary Care: The Role of Relational Coordination.** *Medical decision making : an international journal of the Society for Medical Decision Making*  
Tietbohl, C. K., Rendle, K. A., Halley, M. C., May, S. G., Lin, G. A., Frosch, D. L.  
2015; 35 (8): 987-98
- **Redefining Risk and Benefit: Understanding the Decision to Undergo Contralateral Prophylactic Mastectomy** *QUALITATIVE HEALTH RESEARCH*  
Rendle, K. A. S., Halley, M. C., May, S. G., Frosch, D. L.  
2015; 25 (9): 1251–59
- **Shared clinician- patient decision- making about treatment of pediatric asthma: what do we know and how can we use it?** *CURRENT OPINION IN ALLERGY AND CLINICAL IMMUNOLOGY*  
Rivera-Spoljaric, K., Halley, M., Wilson, S. R.  
2014; 14 (2): 161–67
- **Beyond barriers: fundamental 'disconnects' underlying the treatment of breast cancer patients' sexual health** *CULTURE HEALTH & SEXUALITY*  
Halley, M. C., May, S. G., Rendle, K. A., Frosch, D. L., Kurian, A. W.  
2014; 16 (9): 1169-1180
- **A conceptual model of the multiple stages of communication necessary to support patient-centered care.** *Journal of comparative effectiveness research*  
Halley, M. C., Rendle, K. A., Frosch, D. L.  
2013; 2 (4): 421-33
- **An effort to spread decision aids in five California primary care practices yielded low distribution, highlighting hurdles.** *Health affairs (Project Hope)*  
Lin, G. A., Halley, M., Rendle, K. A., Tietbohl, C., May, S. G., Trujillo, L., Frosch, D. L.  
2013; 32 (2): 311-20
- **The impact of "significant others" on breast cancer patients' treatment decision making.** *Journal of clinical oncology*  
Rendle, K., Halley, M., Ventre, N., Kurian, A. W., Yu, P. P.  
2012; 30 (34): 20-?
- **A regional survey of dentists' preferences for hiring a dental associate.** *Journal of the American Dental Association (1939)*  
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