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PREVIVORSHIP AND MEDICAL UNCERTAINTY

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ABSTRACT

Previvors — those who are not yet sick, but who have a genetic predisposition to disease — face profound uncertainty. This uncertainty complicates decision-making around screening, prevention, and prophylactic interventions. The legal doctrine of informed consent fails to adequately address this uncertainty, presenting problems for respecting previvor autonomy and facilitating informed choices. By applying Uncertainty Management Theory, this Article argues for a new legal standard for informed consent that places greater emphasis on patient comprehension, with the aim of ameliorating some of the inherent uncertainties of previvor decision making.

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I. INTRODUCTION

Genetic testing is becoming increasingly advanced in its ability to predict complex medical conditions. Today, in clinical care, these tests are used to predict the likelihood of developing breast and ovarian cancers as a result of a mutation in the BRCA gene, as well as for other hereditary cancer syndromes, including Lynch Syndrome, Cowden Syndrome, Li-Fraumeni Syndrome, CDH1 mutations, and multiple endocrine neoplasia type 2.[1] Genetic tests are also used to predict hereditary diseases besides cancer, such as Alzheimer's Disease and Huntington's Disease.[2] Genome-wide polygenic risk scores ("PRS") have been validated for common diseases such as coronary artery disease, atrial fibrillation, type 2 diabetes, breast cancer, and inflammatory bowel disease, among others.[3] As PRS calculations become more common in clinical care, more and more individuals will have access to

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[1] Evgeny N. Imyanitov, Ekaterina S. Kuligina, Anna P. Sokolenko, Evgeny N. Suspitsin, Grigoriy A. Yanus, Aglaya G. Iyevleva, Alexandr O. Ivantsov & Svetlana N. Aleksakhina, Hereditary Cancer Syndromes, 14 WORLD J. CLINICAL ONCOLOGY 40, 49, 50 (2023).

[2] For example, an individual may receive genetic testing results indicating that he or she has an increased risk of developing late-onset Alzheimer's Disease, due to the presence of an APOE mutation. *APOE Gene*, MEDLINEPLUS (Mar. 29, 2021), https://medlineplus.gov/genetics/gene/apoe/ [https://perma.cc/JN2L-RXF5].

[3] Amit V. Khera, Mark Chaffin, Krishna G. Aragam, Mary E. Haas, Carolina Roselli, Seung Hoan Choi, Pradeep Natarajan, Eric S. Lander, Steven A. Lubitz, Patrick T. Ellinor & Sekar Kathiresan, *Genome-Wide Polygenic Scores for Common Diseases Identifying Individuals with Risk Equivalent to Monogenic Mutations*, 50 NATURE GENETICS 1219, 1219 (2018); Eleanor Roberts, Sacha Howell & D. Gareth Evans, *Polygenic Risk Scores and Breast Cancer Risk Prediction*, 67 BREAST 71, 71 (2023) ("When incorporated into risk models, the more personalised risk assessment derived from PRS, help identify women at higher risk of breast cancer development and enables the implementation of stratified screening and prevention approaches.").

information about their risks of developing any number of diseases. In turn, they will be faced with an ever-increasing array of complex decisions about how to manage those risks.

In 2013, the actress Angelina Jolie used her fame to bring attention to her decision to undergo a prophylactic double mastectomy, after genetic testing informed her that she was highly susceptible to breast cancer.[4] In a phenomenon branded the "Angelina effect,"[5] her announcement motivated many to get tested for BRCA mutations.[6]

"Previvors" like Jolie — those who are not yet sick, but who have a genetic predisposition to disease[7] — face profound uncertainty as they make decisions about the course of their future care. This uncertainty complicates decision-making around screening, prevention, and prophylactic interventions. The legal doctrine of informed consent[8] fails to adequately address this uncertainty, presenting problems for respecting previvor autonomy and facilitating informed choices. This Article argues for a new legal standard for informed consent that applies Uncertainty Management Theory to place greater emphasis on patient comprehension, with the aim of ameliorating some of the inherent uncertainties of previvor decision making. Assurance of comprehension

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[4] *See* Angelina Jolie, *My Medical Choice*, N.Y. TIMES (May 14, 2013), https://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html [https://perma.cc/CYU6-MK5V]. However, scholars have noted, "[a]lthough her story boosted awareness, it did not enhance understanding of the complex genetic testing, diagnostics, treatments, and medical decisions women like Jolie Pitt are faced with (Borzekowski et al.). As Dean (2016) notes, this lack of understanding could be because the internet and news coverage only focused on Jolie Pitt's unique personal situation." Carla L. Fisher, Thomas Roccotagliata, Camella J. Rising, David W. Kissane, Emily Glogowski & Carma L. Bylund, *"I Don't Want to be an Ostrich": Managing Mothers' Uncertainty During* BRCA1/2 *Genetic Counseling*, 26 J. GENETIC COUNSELING 455, 456 (2017) (citing Dina L.G. Borzekowski, Yue Guan, Katherine C. Smith, Lori H. Erby & Debra L. Roter, *The Angelina Effect: Immediate Reach, Grasp, and Impact of Going Public*, 16 GENETICS MED. 516 (2014)); *see* Marleah Dean, *Communicating in Patient-Provider Relationships*, *in* STORIED HEALTH AND ILLNESS: COMMUNICATING PERSONAL, CULTURAL, AND POLITICAL COMPLEXITIES 53, 61 (Jill Yamasaki, Patricia Geist-Martin & Barbara F. Sharf eds., 2016).

[5] This term was coined by Time Magazine in a cover story after Jolie's announcement. Jeffrey Kluger & Alice Park, *The Angelina Effect*, TIME, May 27, 2013. Researchers found that "[a] celebrity like Angelina Jolie announcing her decision to have a surgical procedure to prevent future cancer may have, to a larger extent, influenced these women facing a degree of uncertainty about future breast cancer risk to proceed more aggressively towards prophylactic surgery." Alexander Liede, Mona Cai, Tamara Fidler Crouter, Daniela Niepel, Fiona Callaghan & D. Gareth Evans, *Risk-Reducing Mastectomy Rates in the U.S.: A Closer Examination of the Angelina Effect*, 171 BREAST CANCER RSCH. & TREATMENT 435, 441 (2018).

[6] Kami A. Kosenko, Andrew R. Binder & Ryan Hurley, *Celebrity Influence and Identification: A Test of the Angelina Effect*, 21 J. HEALTH COMMC'N 318, 324 (2016).

[7] Sue Friedman, *What a Difference a Decade Makes*, FORCE BLOG (Sept. 30, 2010), https://facingourrisk.wordpress.com/2010/09/30/what-a-difference-a-decade-makes/ [https://perma.cc/A4PL-SSTA] ("We invented our own label — cancer previvor — a hybrid between survivor and predisposition to cancer.").

[8] For an overview of the law of informed consent, see Sheldon F. Kurtz, *The Law of Informed Consent: From "Doctor Is Right" to "Patient Has Rights,"* 50 SYRACUSE L. REV. 1243 (2000).

in the informed consent process may help ameliorate some of the uncertainty inherent in medical decision making, particularly in the wake of advancements in medical technologies and their ability to predict the genetic risks of complex conditions.

II. PREVIVORSHIP AS A MODEL OF UNCERTAINTY IN MEDICINE

While today, the term "previvor" is almost exclusively limited to individuals with a mutation in the BRCA genes,[9] I have previously argued for a more expansive definition of the term — one that is inclusive of all individuals with a hereditary mutation, a family history of a specific disease, or some other predisposing factor, for which preventative action or prophylactic interventions can be undertaken.[10]

Communications scholars have studied the sources of, and responses to, uncertainty. Dale Brashers and Timothy Hogan characterize uncertainty as "a perception about insufficient knowledge."[11] Brashers posits that "[u]ncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general."[12]

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[9] Lisa Campo-Engelstein, *BRCA Previvors: Medical and Social Factors that Differentiate Them from Previvors with Other Hereditary Cancers*, 6 BIOÉTHIQUEONLINE 1, 2 (2017). Mutations in the BRCA genes confer an elevated risk of breast, ovarian, and other cancers. *See* Summer C. Martin, Allison M. Scott & Anne M. Stone, *Women's Metaphors About BRCA Testing and How They Can Inform Health Communication Theory and Practice*, 39 HEALTH COMMC'N 603, 603 (2023) ("Among women with a deleterious BRCA mutation, 69–72% develop breast cancer by the time they are 80 years old compared to 13% of women in the general population who develop breast cancer during their lives. Moreover, 17–44% of women with a harmful BRCA mutation develop ovarian cancer by age 80, compared to 1.2% of women in the general population who develop ovarian cancer in their lifetime." (citing Karoline B. Kuchenbaecker, John L. Hopper, Daniel R. Barnes, Kelly-Anne Phillips, Thea M. Mooij, Marie-José Roos-Blom, Sarah Jervis, Flora E. van Leeuwen, Roger L. Milme, Nadine Andrieu, David E. Goldgar, Mary Beth Terry, Matti A. Rookus, Douglas F. Easton & Antonis C. Antoniou, *Risks of Breast, Ovarian, and Contralateral Breast Cancer for* BRCA1 *and* BRCA2 *Mutation Carriers*, 317 J. AM. MED. ASSOC. 2402, 2403 (2017))); Nadia Howlader, Anne-Michelle Noone, Martin Krapcho, David Miller, Ariel Brest, Mandi Yu, Jennifer Ruhl, Zaria Tatalovich, Angela B. Mariotto, Denise Riedel Lewis, Huann-Sheng Chen, Eric J. Feuer & Kathleen A. Cronin, *SEER Cancer Statistics Review, 1975-2017*, NAT'L CANCER INST. (Apr. 15, 2020), https://seer.cancer.gov/csr/1975_2017/ [https://perma.cc/59BX-9Q7W].

[10] For a similar discussion, see Campo-Engelstein, *supra* note 9, at 2 ("Despite the broad definition of previvor, discussions of previvors generally refer to women who have tested positive for one of the BRCA mutations. Yet, there are other hereditary cancers for which prophylactic treatment is available.").

[11] Timothy P. Hogan & Dale E. Brashers, *The Theory of Communication and Uncertainty Management: Implications from the Wider Realm of Information Behavior*, *in* UNCERTAINTY, INFORMATION MANAGEMENT, AND DISCLOSURE DECISIONS 48 (Tamara D. Afifi & Walid A. Afifi eds., Routledge 2009).

[12] Dale E. Brashers, *Communication and Uncertainty Management*, 51 J. COMMC'N 478, 478 (2001); *see also* Dale E. Brashers, Judith L. Neidig, Stephen M. Haas, Linda K. Dobbs,

And uncertainty pervades medicine. Uncertainty in illness was defined by the scholar Merle Mishel as "the inability to determine the meaning of illness-related events."[13] In her seminal work, she explained that uncertainty "occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately."[14] More generally, there is a vast and growing scholarship focusing on the role of uncertainty in medicine. In particular, Paul Han and colleagues[15] and Austin Babrow and colleagues[16] have enumerated taxonomies of uncertainty, in order to better understand (and perhaps manage) medical uncertainty. Both groups recognize that although certain types of uncertainty may be reducible, other types — particularly "probability uncertainty" and "ambiguity uncertainty" — may be irreducible, even when all mandated disclosures have been made.[17] Although uncertainty can "never be entirely

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Linda W. Cardillo & Jane A. Russell, *Communication in the Management of Uncertainty: The Case of Persons Living with HIV or AIDS*, 67 COMMC'N MONOGRAPHS 63, 64 (2000) (stating uncertainty occurs when "events and circumstances [are] marked by unpredictability, ambiguity, or insufficient information").

[13] Merle H. Mishel, *Uncertainty in Illness*, 20 J. NURSING SCHOLARSHIP 225, 225 (1988).

[14] *Id.* at 225.

[15] Paul K.J. Han, William M.P. Klein & Neeraj K. Arora, *Varieties of Uncertainty in Health Care: A Conceptual Taxonomy*, 31 MED. DECISION MAKING 828 (2011) (proposing a taxonomy of uncertainty in medicine that characterizes it according to its fundamental sources, issues, and locus). Further, Mary Politi and colleagues also identify five types or sources of uncertainty: (1) risk, or uncertainty about future outcomes; (2) ambiguity, or uncertainty about the strength or validity of evidence about risks; (3) uncertainty about the personal significance of particular risks (e.g., their severity, timing); (4) uncertainty arising from the complexity of risk information (e.g., the multiplicity of risks and benefits or the instability of risks and benefits over time); and (5) uncertainty resulting from ignorance). Mary C. Politi, Paul K.J. Han & Nananda F. Col, *Communicating the Uncertainty of Harms and Benefits of Medical Interventions*, 27 MED. DECISION MAKING 681, 682 (2007).

[16] Austin S. Babrow, Chris R. Kasch & Leigh A. Ford, *The Many Meanings of* Uncertainty *in Illness: Toward a Systematic Accounting*, 10 HEALTH COMMC'N 1, 17–18 (1998). Newson and colleagues reflect on both Babrow et al. and Han et al.'s approaches to medical uncertainty, explaining, "Babrow et al.'s first and second forms of uncertainty overlap with Han et al.'s three sources of uncertainty. In their third, fourth and fifth forms, Babrow et al. seem to more explicitly recognize the experiential or subjective properties of uncertainty." Ainsley J. Newson, Samantha J. Leonard, Alison Hall & Clara L. Gaff, *Known Unknowns: Building and Ethics of Uncertainty into Genomic Medicine*, 9 BMC MED. GENOMICS, 3, 7 (2016).

[17] As described by Ainsley Newson and colleagues, (1) *probability* uncertainty "occurs where there is indeterminacy of future outcomes[,]" (2) *ambiguity* uncertainty "arises when the information or evidence is imprecise, where there is conflicting opinion or where information is not known[,]" and (3) *complexity* uncertainty "arises when there are features of the available information that make it hard to understand." Newson et al., *supra* note 16, at 2 (summarizing Han et al., *supra* note 15). However, irreducible uncertainty may be manageable. *See id.* at 2; *see also* Rachel H. Gore, John F.P. Bridges, Julie S. Cohen & Barbara B. Biesecker, *Challenges to Informed Consent for Exome Sequencing: A Best-Worst Scaling Experiment*, 28 J. GENETIC COUNSELING 1189, 1195 (2019) ("While uncertainty cannot be eliminated from exome sequencing, providers have an opportunity to help patients understand differing sources of ambiguity and identify areas where they can attempt to find control in the face of uncertainty. These ideas may be particularly helpful if explored during pretest

eliminated for previvors,"[18] efforts to address the reducible uncertainty can help patients make better, more voluntary decisions about their medical futures.

Patients, and previvors in particular, may also experience longstanding uncertainty. Uncertainty becomes chronic when one must manage unpredictability, ambiguity, or inconsistency over extended periods of time.[19] Further, information needs change during a patient's healthcare journey,[20] which can frequently exacerbate feelings of uncertainty.

Uncertainty is particularly pronounced for the previvor. Previvorship, like other categories before it, challenges the biomedical model of illness, underscoring problems that focus solely on medical risk.[21] Previvors often struggle to manage their uncertainty[22] and are "faced with uncertainty about their risk management."[23] Further, studies have demonstrated that previvors' decision making is often driven by psychosocial factors, "such as feelings of guilt and vulnerability and the degree of perceived social support."[24] In other words, the uncertainty previvors experience goes beyond the medical. They "often experience . . . familial uncertainty, or anxieties from traumatic family cancer memories and motherhood, and may seek out information and support to help make complex decisions about genetic testing, timing, family

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counseling so that patients can begin to build a concept of uncertainty prior to receiving such a result." (citations omitted)).

[18] Josephine K. Boumis & Marleah Dean, *The* BRCA1/2 *Previvor Information Journey: Understanding What Helps or Hinders*, 39 HEALTH COMMC'N 1942, 1942 (2023).

[19] *See* Brashers, *supra* note 12, at 478.

[20] *See* Marleah Dean, Courtney Scherr, Meredith Clements, Rachel Korou, Jennifer Martinez & Amy Ross, *"When Information is Not Enough": A Model for Understanding BRCA-Positive Previvors' Information Needs Regarding Hereditary Breast and Ovarian Cancer Risk*, 100 PATIENT EDUC. & COUNSELING 1738, 1742 (2017).

[21] *See* Gayle A. Sulik, *Managing Biomedical Uncertainty: The Technoscientific Illness Identity*, 30 SOCIO. HEALTH & ILLNESS 1059, 1062 (2009) ("A person may unexpectedly learn (or even seek out the knowledge) that she is predisposed to a particular medical condition, or is a genetic carrier of a disease. Instead of simply acknowledging the biomedical marker as a piece of information, the person begins to think of herself as pre-diseased.").

[22] *See* Ashley Farrelly, Victoria White, Bettina Meiser, Michael Jefford, Mary-Anne Young, Sandra Ieropoli, Ingrid Winship & Jessica Duffy, *Unmet Support Needs and Distress Among Women with a* BRCA1/2 *Mutation*, 12 FAMILIAL CANCER 509, 510 (2013); Boumis & Dean, *supra* note 18, at 1942.

[23] Meghan L. Underhill & Cheryl B. Croster, *Seeking Balance: Decision Support Needs of Women Without Cancer and a Deleterious* BRCA1 *or* BRCA2 *Mutation*, 23 J. GENETIC COUNSELING 350, 358 (2013).

[24] Sharlene Hesse-Biber & Chen An, *Genetic Testing and Post-Testing Decision Making among BRCA-Positive Mutation Women: A Psychosocial Approach*, 25 J. GENETIC COUNSELING 978, 978 (2016); *see also id.* at 986 ("[The] 'nexus of decision making' . . . includes social factors (such as family and support networks) and psychological factors (such as feelings and internal reactions to the test result).").

planning, and overall quality of life."[25] Because of the non-medical aspects of previvor decision making, previvors occupy a "nexus of decision making" routed in psychosocial factors and social network engagements, which "does not, for the most part, mirror . . . the specific treatment protocols outlined by the medical establishment."[26]

III. PREVIVORSHIP CHALLENGES THE CURRENT DOCTRINE OF INFORMED CONSENT

The legal doctrine of informed consent requires that physicians disclose the risks, benefits, and alternatives of a proposed intervention to patients.[27] Patients — and in particular, previvors — navigate both risk and uncertainty when making decisions about whether to undergo medical interventions.[28] Significantly, risk and uncertainty are distinct concepts: risk refers to the probabilities associated with the possible outcomes that are assumed to be known or measurable, while uncertainty refers to probabilities that are assumed to be unknown or immeasurable.[29] In other words, uncertainty is about not having complete information or knowledge, while risk involves the quantification of the likelihood of specific outcomes. Studies have found that previvors struggle with feelings of uncertainty in understanding their diagnosis and in making decisions.[30]

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[25] Mariah L. Wellman, Avery E. Holton & Kimberly A. Kaphingst, *Previvorship Posting: Why Breast Cancer Previvors Share Their Stories on Social Media*, 38 HEALTH COMMC'N 2441, 2442 (2023) (citing Dean, *supra* note 4, at 54; *see also* Marleah Dean & Emily A. Rauscher, *"It was an Emotional Baby": Previvors' Family Planning Decision-Making Styles about Hereditary Breast and Ovarian Cancer Risk*, 26 J. GENETICS COUNSELING 1301, 1302 (2017)).

[26] Hesse-Biber & An, *supra* note 24, at 978.

[27] *See* Canterbury v. Spence, 464 F.2d 772, 780 (D.C. Cir. 1972); Cobbs v. Grant, 502 P.2d 1, 8 (Cal. 1972); *see also* JESSICA W. BERG, CHARLES W. LIDZ, LISA S. PARKER & PAUL S. APPELBAUM, INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE 133–34 (2d ed. 2001). The term "informed consent" — and with it, a proposed duty to disclose — first appeared in 1957 in the California case *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs*., 317 P.2d 170 (Cal. Ct. App. 1957), which held that physicians had a duty to disclose all facts that were necessary for the patient to make an intelligent health care decision. *See also* Kurtz, *supra* note 8, at 1246–47.

[28] "BRCA1/2 previvors are faced with difficult medical decisions after being diagnosed including whether to undergo a prophylactic mastectomy, a prophylactic oophorectomy resulting in early menopause, chemoprevention, or to begin aggressive cancer screening regimens. Some may elect watchful waiting or even elect to do nothing at all." Wellman et al., *supra* note 25, at 2441.

[29] *See* FRANK H. KNIGHT, RISK, UNCERTAINTY, AND PROFIT 19–20 (1921) ("Uncertainty must be taken in a sense radically distinct from the familiar notion of Risk, from which it has never been properly separated."); Amos Tversky & Craig R. Fox, *Weighing Risk and Uncertainty*, 102 PSYCH. REV. 269, 269 (1995).

[30] *See* Marleah Dean, "It's Not if I Get Cancer, It's When I Get Cancer": Exploring Previvors' Management of Uncertainty for Hereditary Cancer in Clinical Encounters 2 (Aug. 2014) (Ph.D. dissertation, Texas A&M University) (on file with the Texas A&M University Library system).

While the law has been modified and adapted to ensure that risk disclosures are adequate,[31] it remains woefully inadequate in addressing the uncertainty inherent in complex medical decision making. In other words, informed consent disclosures focus on the physician's affirmative disclosures of the degree and incidence of risk: those known, statistical numbers that can be identified.[32] In contrast, the legal doctrine of informed consent does not address the reduction or management of patient uncertainty. Rather than focusing on the patient — what the patient understands and how the patient makes decisions — the law looks only to the physician's behavior — what the physician says and does. If we shift the emphasis to the patient, we can also begin to incorporate uncertainty into the calculus.

It is increasingly imperative that we address the uncertainty inherent in decision making. Scholars have recognized that "remaining in intense states of constant uncertainty can be harmful for one's health."[33] Thus, "helping previvors successfully manage this uncertainty is crucial" to improving health outcomes.[34]

A. The Law Overemphasizes Unidirectional Disclosures

However, the legal doctrine of informed consent, with its formulaic emphasis on unidirectional physician disclosures, has proven inadequate to addressing previvor uncertainty.[35] Previvorship challenges some of the most basic assumptions about the legal doctrine of informed consent and the expectations of the traditional patient role. Because of the unique levels of uncertainty inherent to the previvor experience, the contours of the legal doctrine of informed consent may be inadequate to ensure individual self-determination in medical decision making.

This inadequacy is because, generally, the doctrine of informed consent focuses almost exclusively on disclosures of risk and probabilities. Thus, for previvors, we might ask: What is the likelihood that a BRCA positive patient will develop breast cancer in five years absent prophylactic action? What about in ten years? Twenty? How much risk will be reduced if the patient undergoes a prophylactic double

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[31] *See* Nadia N. Sawicki, *Modernizing Informed Consent: Expanding the Boundaries of Materiality*, 2016 U. ILL. L. REV. 821 (2016) (addressing efforts to modify informed consent disclosures to include non-medical risks and benefits, such as physicians' personal characteristics, the cost of treatment, the social and ethical implications of various health care interventions, and the legal consequences associated with diagnosis and treatment).

[32] *See* BERG ET AL., *supra* note 27, at 55–57.

[33] Boumis & Dean, *supra* note 18, at 1942; *see also* Laura E. Miller, *Uncertainty Management and Information Seeking in Cancer Survivorship*, 29 HEALTH COMMC'N 233, 233 (2014).

[34] Boumis & Dean, *supra* note 18, at 1942.

[35] *See* Valerie Gutmann Koch, *Previvors*, 49 FLA. STATE L. REV. 643, 681 (2022).

mastectomy? What if, instead, the previvor chooses surveillance, or regular screening for early signs of breast cancer through mammograms and MRIs?

But these disclosures may do little to address patient uncertainty. As Dale Brashers explains,

> Lacking knowledge is somewhat independent of self-assessment about one's state of knowledge; I may have a great deal of knowledge about a topic, I may have an amount of information that other people would deem sufficient to make a decision or to predict another's behavior, and I even may have all the information that is currently available, yet I still may feel uncertain.[36]

As Brashers explains, patients may continue to feel uncertainty even with all available information being provided to them. In other words, disclosure or transmission of information is not enough to counter or alleviate uncertainty. And adding more information to the disclosure process may not address uncertainty either. Rather, increasing disclosures can lead to information overload.[37] As is the case with informed consent disclosures more generally, information overload can lead previvors to feel that "available information [is] too overwhelming . . . , unmanageable, and "isolating."[38] Studies have found information overload among BRCA previvors.[39]

Most research related to previvors' needs has focused on information disclosure.[40] However, in a 2023 study, Professors Josephine Boumis and Marleah Dean found that "previvors commonly experience information needs surrounding living with and understanding *BRCA*."[41] They concluded, "Previous research has presumed that fulfilling previvors' information needs will lower their uncertainty and therefore be helpful to previvors. However, it is possible that previvors believe they

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[36] Brashers, *supra* note 12, at 478.

[37] Overload occurs when an individual's processing capacity is exceeded by the volume of information presented. Israa Khaleel, Barbara C. Wimmer, Gregory M. Peterson, Syed Tabish Razi Zaidi, Erin Roehrer, Elizabeth Cummings & Kenneth Lee, *Health Information Overload Among Health Consumers: A Scoping Review*, 103 PATIENT EDUC. & COUNSELING 15, 16 (2020); *see* John Sweller, *Cognitive Load During Problem Solving: Effects on Learning*, 12 COGNITIVE SCI. 257, 276 (1988).

[38] Boumis & Dean, *supra* note 18, at 1948.

[39] *See* Audrey Ardern-Jones, R. Kenen & R. Eeles, *Too Much, Too Soon?, Patients and Health Professionals Views Concerning the Impact of Genetic Testing at the Time of Breast Cancer Diagnosis in Women Under the Age of 40*, 14 EUR. J. CANCER CARE 272, 279 (2005).

[40] For example, in a 2008 study, previvors expressed needing more information concerning their risk levels and guidelines for both testing and prevention, as well as needing more support. Allison Werner-Lin, *Formal and Informal Support Needs of Young Women with BRCA Mutations*, 26(4) J. PSYCHOSOCIAL ONCOLOGY 111 (2006).

[41] Boumis & Dean, *supra* note 18, at 1943.

want their information needs met, but their perceptions of how helpful that information is changes once they actually begin to learn more."[42]

Although "[c]ommunicating risk information is intended to reduce uncertainty about the likelihood of disease and death by allowing people to estimate those probabilities,"[43] "simply providing information to previvors is not sufficient to assist in coping with their high genetic risk."[44] In fact, having all available information may not eliminate uncertainty.[45] Previvors may have all currently available medical information but may still not know whether they will develop the disease(s) to which they are genetically predisposed. Because the legal doctrine of informed consent has its focus on mandated information disclosures, the doctrine is incapable of assisting individuals in coping with irreducible uncertainty. Thus, existing rules are inappropriate to the types of decisions that previvors face because "[t]he needs of this group are different from those actually diagnosed with cancer" and other illnesses.[46]

Experts on medical decision making have observed the hazards of focusing on disclosures. For example, Gretchen Schwarze and colleagues have explained,

> Knowledge is power, but the notion that hierarchical relationships can be mitigated by providing reams of medical information is flawed. While this pattern likely reflects a desire to support autonomy or somehow meet criteria for informed consent, it is not possible to transfer deep knowledge gained through years of training and experience. It is hard to imagine that patients could learn enough about anatomy, pathology, and surgery to make their own assessment about whether an operation is a good idea.[47]

Previvors — and patients across various disease states and circumstances — have clearly expressed the need for their decisions to be based not solely on medical risks and probabilities. Rather, previvors

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[42] *Id.*

[43] Brashers, *supra* note 12, at 486–87.

[44] Dean et al., *supra* note 20, at 1742. *See also* Soo Jung Hong, *Uncertainty in the Process of Communicating Cancer-Related Genetic Risk Information with Patients: A Scoping Review*, 25 J. HEALTH COMMC'N 251, 251 (2020) ("[U]ncertainty related to genetic risk information is caused in part by uncertainty's probabilistic nature, which includes ambiguity and complexity." (citation omitted)).

[45] *See* Dean, *supra* note 30, at 8.

[46] Suzanne M. Mahon, *Impact of the Genetic Screening Revolution: Understanding and Meeting the Needs of Previvors with a Known Family Mutation in* BRCA1/BRCA2, 14 EVIDENCE-BASED NURSING 126, 127 (2011).

[47] Margaret L. Schwarze, Justin Clapp & Robert M. Arnold, *Innovations in Surgical Communication 3 — Promote Deliberation, Not Technical Education*, 158 JAMA SURGERY 997, 997 (2023).

filter this information "through a broader lens of personal experiences and preferences."[48]

This change in emphasis away from focusing on disclosures aligns with previous calls for a shift to a shared decision making approach to medical decisions, particularly for the previvor.[49] Shared decision making, introduced as an alternative to the purely autonomy-focused informed consent model of medical decision making in the late twentieth century, "includes the notion of a medical encounter as a 'meeting of experts' — the physicians as an expert in medicine and the patient as expert in his or her own life, values and circumstances."[50] Shared decision making is subjective and patient specific, relying "on the medical evidence, the provider's clinical expertise, and the unique attributes of the patient and his or her family[,]" including cultural factors and factors that affect patient-clinician interactions.[51]

IV. INCORPORATING COMPREHENSION INTO THE LEGAL DOCTRINE OF INFORMED CONSENT MAY HELP PREVIVORS MANAGE UNCERTAINTY IN MEDICAL DECISIONS

Previous work has focused on the need for a shift to a shared decision-making model to address many of the insufficiencies in the current legal doctrine of informed consent.[52] However, true shared decision

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[48] Mariah L. Wellman, Avery E. Holton & Kimberly A. Kaphingst, *"Where Do I Go? Who Do I Go To?": BRCA Previvors, Genetic Counselors and Family Planning*, 2 PEC INNOVATION 1, 2 (2023) (citing Sharlene Hesse-Biber, *The Genetic Testing Experience of BRCA-Positive Women: Deciding Between Surveillance and Surgery*, 24 QUALITATIVE HEALTH RSCH. 773, 785 (2014)). "[Previvor] decisions [are] more than just having surgery or surveillance and include[] complex factors related to the person, family, procedure, and health care system. Emotional and physical consequences of these decisions, both actual and potential, [are] important to the decision making process and require ongoing, long-term support and assessment by health care professionals." Meghan L. Underhill & Cheryl B. Crotser, *Seeking Balance: Decision Support Needs of Women without Cancer and a Deleterious* BRCA1 *or* BRCA2 *Mutation*, 23 J. GENETIC COUNSELING 350, 361 (2013).

[49] *See* Koch, *supra* note 35, at 682–89.

[50] William Godolphin, *Shared Decision-Making*, 12 HEALTHCARE Q. 186, 186 (2009) (citing DAVID TUCKETT, MARY BOULTON, CORAL OLSON & ANTHONY WILLIAMS, MEETINGS BETWEEN EXPERTS: AN APPROACH TO SHARING IDEAS IN MEDICAL CONSULTATIONS (1985)).

[51] France Légaré & Holly O. Witteman, *Shared Decision Making: Examining Key Elements and Barriers to Adoption into Routine Clinical Practice*, 32 HEALTH AFFS. 276, 277 (2013). It is also imperative to recognize "the ever changing, temporal nature of decision support needs experienced by these women. Therefore, interventions created to aid persons with HBOC risk should also be dynamic, customizable and iterative to allow for continued improvement, updates, and specifications as both patient preferences and the scientific body of evidence change." Underhill & Crotser, *supra* note 48, at 360. Disclosures are therefore insufficient to meet the needs of previvors making life-altering decisions over time.

[52] *See* Godolphin, *supra* note 50; Légaré & Witteman, *supra* note 51; *see also* Underhill & Crotser, *supra* note 48, at 360 ("Values clarification is an important component of the decision making process for women who are uncertain about what action to take to manage risk.").

making (or informed consent) is impossible unless the previvor comprehends the information communicated during the decision making process.[53]

The informed consent process should be, at its core, about communication between the clinician and the patient. Scholars have developed theories of communication science intended to reduce or manage uncertainty in medical decision making. Here, I apply one of those theories, Uncertainty Management Theory ("UMT") to previvor decision making to improve the doctrine of informed consent.[54]

A. UMT as a Lens for Understanding Previvor Uncertainty

UMT was developed to address "communication processes in the management of illness-related uncertainty" to offer "a means to sort through and make sense of the relationships that exist between the experience of uncertainty and interaction with information."[55] Scholars of UMT argue that while some uncertainty may be reduced, some uncertainty is better managed, which can allow people to maintain hope and optimism.[56] Communications scholars have developed and applied UMT to address uncertainty as it pervades certain aspects of life, and in particular, medical decision making.[57] In other words, "[r]ather than assuming that individuals invariably seek information for the purpose of reducing uncertainty, it is more accurately claimed that they desire to manage their uncertainty."[58]

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[53] Valerie Gutmann Koch, *Reimagining Informed Consent: From Disclosure to Comprehension*, 14 U.C. Irvine L. Rev. (forthcoming 2024).

[54] *See* Boumis & Dean, *supra* note 18, at 1952 ("Given the longevity of a previvor's information journey, future research utilizing the [UMT] in this context or other similar health contexts should account for chronic uncertainty and the role it may play in engaging both strategies.").

[55] Hogan & Brashers, *supra* note 11, at 45–46.

[56] *See* Dale E. Brashers & Austin S. Babrow, *Theorizing Communication and Health*, 3 COMMC'N STUD. 243, 246 (1996). *But see* Austin S. Babrow & Marianne S. Matthias, *Generally Unseen Challenges in Uncertainty Management*, *in* UNCERTAINTY, INFORMATION MANAGEMENT, AND DISCLOSURE DECISIONS 20–21 (Tamara D. Afifi & Walid A. Afifi eds., 2009) (asserting that the notion that uncertainty is a thing that should be "managed" is "limiting as it implies "that uncertainty is inherently an experience that can and should be controlled" and arguing for the use of the phrase "coping with uncertainty" rather than "managing uncertainty").

[57] *See* Austin S. Babrow & Anne M. Stone, *Theories of Communication and Uncertainty as a Foundation for Future Research on Nursing Practice*, 1 NURSING COMMC'N 11, 13 (2020) (recognizing that "uncertainty management" involves a wider variety of motivations than just uncertainty reduction); Terrance L. Albrecht & Mara B. Adelman, *Social Support and Life Stress: New Directions for Communication Research*, 11 HUM. COMMC'N RSCH. 3 (1984); Brashers & Babrow, *supra* note 56, at 243.

[58] James Price Dillard & Christine L. Carson, *Uncertainty Management Following a Positive Newborn Screening for Cystic Fibrosis*, 10 J. HEALTH COMMC'N 57, 60 (2005) ("Individuals are likely to experience frustration when the amount of information they desire does not match the amount of information they are given." (citation omitted)); Miller, *supra* note

Improved communication strategies advance patient comprehension. Using UMT "brings to the forefront how the experience of uncertainty is ultimately a communicative one. How we manage uncertainty is an interactive process."[59] UMT scholars such as Brashers have "noted the importance of formulating strategies for the delivery of information about health risk (which can result in uncertainty) to patients in ways that facilitate better processing and understanding while abating distress."[60]

More recently, UMT has been applied to analyze how patients make decisions to undergo genetic testing decision and their subsequent choices as previvors.[61] UMT may help those who support previvor decision making processes. For example, "[g]iven that some previvors experience information overload when seeking information, it may be useful to develop interventions that teach previvors not only how to find information but also how to manage and evaluate the information."[62]

UMT posits that individuals seek and avoid information in an effort to manage their uncertainty.[63] As Professor Brashers and colleagues explain, "Information seeking is important if an individual's management goal is reduction of uncertainty . . . . Managing uncertainty also may require information seeking to locate contrary or disconfirming evidence when a person wants to escalate uncertainty."[64] One study of

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33, at 234 ("Research suggests that information management is a common response to uncertain illness situations. Upon diagnosis, individuals are presented with a great deal of information and they must comprehend and manage multiple information sources") (discussing Mishel, supra note 13 and Merle H. Mishel, *Reconceptualization of the Uncertainty in Illness Theory*, 22 IMAGE: J. NURSING SCHOLARSHIP 256 (1990)).

[59] Fisher et al., *supra* note 4, at 456.

[60] Martin et al., *supra* note 9, at 604 (discussing Brashers, *supra* note 12, at 478).

[61] *See* Marleah Dean & Carla L. Fisher, *Uncertainty and Previvors' Cancer Risk Management: Understanding the Decision-Making Process*, 47 J. APPLIED COMMC'N RSCH. 460, 461 (2019).

[62] Boumis & Dean, *supra* note 18, at 10.

[63] *See* Stephen A. Rains & Riva Tukachinsky, *Information Seeking in Uncertainty Management Theory: Exposure to Information About Medical Uncertainty and Information-Processing Orientation as Predictors of Uncertainty Management Success*, 20 J. HEALTH COMMC'N 1275, 1276 (2015) ("One strategy that appears to be particularly important to uncertainty management in UMT is information seeking." (citing Dale E. Brashers, Judith L. Neidig & Daena J. Goldsmith, *Social Support and the Management of Uncertainty for People Living with HIV or AIDS*, 16 HEALTH COMMC'N 305, 311–13 (2004))); Brashers et al., *supra* note 12, at 77; Denise DeLorme & Jisu Huh, *Seniors' Uncertainty Management of Direct-to-Consumer Prescription Drug Advertising Usefulness*, 24 HEALTH COMMC'N 494, 496 (2009); Dillard & Carson, *supra* note 58, at 60–62 (interviewing parents whose newborn had recently received a positive screening for cystic fibrosis and reported that parents actively sought information to learn about the disease); Erin Donovan-Kicken & Jennifer J. Bute, *Uncertainty of Social Network Members in the Case of Communication-Debilitating Illness or Injury*, 18 QUALITATIVE HEALTH RSCH. 5, 5 (2008) (finding that information seeking was an uncertainty-management strategy used among individuals facing communication-debilitating illnesses).

[64] Brashers et al., *supra* note 12, at 77; *see also* Rains & Tukachinsky, *supra* note 63, at 1276 ("Although research has tended to focus on information seeking as means for reducing

patients' exposure to medical information related to skin cancer found that "[i]nformation-processing orientation, which was conceptualized as an artifact of appraisal, was a significant predictor of uncertainty management success . . . . [I]ndividuals who engaged in more systematic processing reported being closer to their ideal uncertainty level post-search."[65] The authors concluded, "The increased effort associated with engaging in systematic processing and closely evaluating . . . content may have enabled study participants to manage their uncertainty more effectively."[66]

Thus, applying UMT may enable individuals to engage in more careful, deliberate, and reasoned processing (i.e., "systematic processing") to manage the uncertainty inherent in previvors' decision making.[67] Further, knowledge about the role of uncertainty in previvors' medical decisions can "be used to develop decision tools that help [patients] process their uncertainty, build skills central to uncertainty and risk management, and allow them to compare their risk-reducing (and uncertainty management) choices."[68]

B. Including Comprehension as an Element of Informed Consent May Help Manage Previvor Uncertainty

Scholars across disciplines recognize that managing uncertainty is an interactive process, and that communication is key.[69] It cannot be unilateral: it requires a give and take; comprehensibility and

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uncertainty, UMT is unique in that it recognizes that information may also be sought to increase one's uncertainty.").

[65] Rains & Tukachinsky, *supra* note 63, at 1284. The authors define "information-processing orientation" as "as the degree to which information seekers engage in systematic or heuristic processing during a search." *Id.* at 1278.

[66] This study, however, focused specifically on use of the web to manage medical forms of uncertainty. The authors note that it would be valuable to explore the role of information seeking to manage uncertainty in different contexts. Researchers might consider information seeking related to social forms of uncertainty or in seeking information after a visit to one's doctor. Rains & Tukachinsky, *supra* note 63, at 1285.

[67] Systematic processing stands in contrast to "heuristic processing," in which individuals respond to cues to more efficiently manage message content. Shelly Chaiken, *Heuristic Versus Systematic Information Processing and the Use of Source Versus Message Cues in Persuasion*, 39 J. PERSONALITY & SOC. PSYCHIATRY 752 (1980).

[68] Dean & Fisher, *supra* note 61, at 461 (discussing Tasleem J. Padamsee, Celia E. Wills, Lisa D. Lee & Electra D. Paskett, *Decision Making for Breast Cancer Prevention Among Women at Elevated Risk*, 19 BREAST CANCER RSCH. (2017)).

[69] *See* Wen-Ying Sylvia Chou, Jessica Tiner & Nicole Senft, *Emerging Challenges in Advanced Cancer Care: Opportunities for Enhancing Patient-Centered Communication*, *in* PSYCHOLOGICAL ASPECTS OF CANCER 207 (Jennifer L. Steel & Brian I. Carr eds., 2022) (noting that communication is critical for those being genetically tested for hereditary breast and ovarian cancer).

comprehension,[70] disclosure and understanding. Theories such as UMT highlight the importance of communication to the informed consent process for previvors, who are often information seekers.[71]

In previous scholarship, I have proposed reforming the legal doctrine of informed consent, by shifting away from the exclusive focus on physician disclosures and shifting toward a standard that emphasizes patient comprehension.[72] This modification may help realize the ethical promise of informed consent by ensuring that patients' decisions are voluntary and autonomous.[73] The law's onerous legal requirements necessitate over-disclosure at the expense of patient understanding.

While tailoring disclosures to the previvor may begin to address some uncertainty, ensuring comprehension of this information will go even farther in improving the previvor experience. A 2023 study of the previvor information journey found that participants described how information or knowledge led them to feel empowered, by enriching their understanding.[74] Participants expressed that the information empowered them to understand more about the risk management options for their genetic variant and potential cancer. And increased understanding means increased control over one's future. Thus, without understanding the information disclosed, previvors are unable to make the informed decisions that will benefit them throughout their journey.

The same study found that increased information provision improved patient decision making: "[p]articipants acknowledged how finding information made them confident with cancer risk management decisions in the beginning of their information journey. For instance,

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[70] *See* Eline M. Bunnik, *No Need for Options for Choice for Unsolicited Findings in Informed Consent for Clinical Genetic Testing*, 31 EUR. J. HUM. GENETICS 1095, 1095 (2023) ("In pre-test discussions between physicians and patients, therefore, full disclosure of all information about genetic testing would simply be impossible. Clearly, a balance must be sought between 'comprehensiveness and comprehensibility.").

[71] Previvors are often the ones who proactively seek information from various sources and seek interventions directly from specialists. The previvor assumes some level of responsibility for their health, which means that many previvors "have determined their preferred course of management before consulting a care provider." Lynn C. Hartmann & Noralane M. Lindor, *The Role of Risk-Reducing Surgery in Hereditary Breast and Ovarian Cancer*, 374 NEW ENG. J. MED. 454, 466 (2016) (citing Sandra van Dijk, Mariëlle S. van Roosmalen, Wilma Otten & Peep F.M. Stalmeier, *Decision Making Regarding Prophylactic Mastectomy: Stability of Preferences and the Impact of Anticipated Feelings of Regret*, J. CLINICAL ONCOLOGY 2358 (2008)).

[72] *See* Koch, *supra* note 53 (proposing and analyzing possible approaches to measuring and ensuring comprehension). This piece proposes and analyzes possible approaches to measuring and ensuring comprehension.

[73] This idea originated with the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which stated that "Ethically valid consent is a process of shared decision making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments." PRESIDENT'S COMM'N FOR STUDY ETHICAL PROBS. MED. & BIOMEDICAL & BEHAV. RSCH., MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP (1982).

[74] *See* Boumis & Dean, *supra* note 18, at 1946.

some participants mentioned how information helped them to make decisions.[75] But if previvors do not understand this information, their decision making will suffer,[76] and individuals may feel less secure in the choices they make.

Any approach must ensure that existing law is appropriately modified to remove existing incentives that promote the formalistic disclosure of information from doctors to patients.[77] Rather, the legal doctrine of informed consent should increasingly emphasize the patient's awareness and understanding of all material information. Application of UMT to previvor decision making supports the need to ensure comprehension in the doctor-patient communication to address uncertainty. Updating the legal doctrine of informed consent may help reflect how previvors — and patients generally — process risk information and manage uncertainty, thereby more effectively aligning the law with the ethical values of ensuring voluntary, informed decision making.[78]

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[75] *Id.* at 1947.

[76] *See* Martin J. Eppler & Jeanne Mengis, *The Concept of Information Overload: A Review of Literature from Organization Science, Accounting, Marketing, MIS, and Related Disciplines*, 5 INFORMATION SOC'Y 325 (2004); Gloria Phillips-Wren & Monica Adya, *Decision Making Under Stress: The Role of Information Overload, Time Pressure, Complexity, and Uncertainty*, 29 J. DECISIONS SYS. 213, 219 (2020).

[77] *See, e.g.*, Frank M. McClellan, James E. Wood & Sherin M. Fahmy, *It Takes a Village: Reforming Law to Promote Health Literacy and Reduce Orthopedic Health Disparities*, 8 J. HEALTH & BIOMEDICAL L. 333, 368–72 (2013). The authors stated that "the legal doctrine of informed consent" may impede shared decision-making. However, they noted,"[t]here is nothing in existing legal statues or court decisions that precludes . . . shared decision-making." However, they recognize that the "concept of the physician-patient relationship as one that should be guided primarily by the importance of deferring to a patient's autonomy has broad implications that may affect the conduct of health care providers and community health workers in a way that discourages active efforts to influence decision-making and behavior." *Id.* at 368; *see also* Ann S. O'Malley, Emily R. Carrier, Elizabeth Docteur, Alison C. Shmerling & Eugene C. Rich, *Policy Options to Encourage Patient-Physician Shared Decision Making*, NAT'L INST. HEALTH CARE REFORM (Sept. 20, 2011), https://nihcr.org/wp-content/uploads/2015/03/NIHCR_Policy_Analysis_No._5.pdf [https://perma.cc/46C4-JSKX] ("Current U.S. legal standards in many ways inhibit shared decision making.").

[78] Importantly, the most recent draft of the Restatement Third of Torts recognizes "Informed consent is an area where law notably has led, rather than followed, professional practice" and had a "pronounced influence . . . on foundational aspects of medical practice . . . ." RESTATEMENT (THIRD) OF TORTS: MEDICAL MALPRACTICE Reporters' Special Note to §§ 12 and 13 on Ethical Idealism versus Legal Pragmatism in Informed Consent Law (AM. L. INST., Tentative Draft No. 1, 2023).