

2019

## Solving the Uncertainty: Why the HIPAA Privacy Rule Fails to Appropriately Address Disclosures of Psychotherapy Notes of Deceased Patients

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### Recommended Citation

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SOLVING THE UNCERTAINTY: WHY  
THE HIPAA PRIVACY RULE FAILS TO  
APPROPRIATELY ADDRESS  
DISCLOSURES OF PSYCHOTHERAPY  
NOTES OF DECEASED PATIENTS

*Elizabeth Burnett*<sup>†</sup>

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## INTRODUCTION

While the Health Insurance Portability and Accountability Act (HIPAA) and its Privacy Rule address many aspects of the privacy of psychotherapy notes, federal legislation and regulation lack express provisions about the uses and disclosures of psychotherapy notes of deceased patients. When a patient dies, the current procedure for mental health professionals is to follow HIPAA, individual state laws, and professional ethical guidelines.<sup>1</sup> The provisions within the Privacy Rule that address uses and disclosures of deceased individuals' records, however, are ambiguous and conflicting – specifically in situations where the mental health professional never received any prior instructions from the patient regarding disclosure of the notes to another person. Thus, the lack of clear regulation in the Privacy Rule presents many open questions for mental health professionals when they receive requests from the deceased's family members or personal representatives to access the deceased individual's psychotherapy notes.

Because the law currently provides unclear guidance, mental health professionals generally must use professional judgment when faced with requests for psychotherapy notes of deceased patients.<sup>2</sup> Professional judgement means the mental health professional must balance the risks and benefits of disclosing the notes when receiving requests for disclosure of a deceased person's records.<sup>3</sup> For example, if the mental health professional determines that the client would have given consent to sharing the requested information with the surviving spouse, and has some prior documentation to that effect, the mental health professional will likely disclose the psychotherapy notes to the surviving spouse.<sup>4</sup> The common and accepted practice in any scenario is to err on the side

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1. See Chris Dimick, *Accessing Deceased Patient Records—FAQ*, J. AHIMA (Apr. 1, 2013), <http://journal.ahima.org/2013/04/01/accessing-deceased-patient-health-records-faq/>.
  2. See *Personal Representatives*, U.S. DEP'T HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/forprofessionals/privacy/guidance/personal-representatives/index.html> (last reviewed Sept. 19, 2013); see also *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, U.S. DEP'T HEALTH & HUM. SERV., at 2 <https://www.hhs.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf> (last visited Mar. 1, 2018).
  3. Richard Leslie, *Confidentiality/Privilege – Death of the Patient*, CPH & ASSOCIATES: AVOIDING LIABILITY BLOG (Nov. 2008), <https://www.cphins.com/confidentialityprivilege-death-of-the-patient/>.
  4. David Kaplan, *Obligations for Protecting the Confidentiality of the Deceased*, COUNSELING TODAY (Oct. 7, 2006), <https://ct.counseling.org/2006/10/ct-online-ethics-update-5/>.

of protecting confidentiality and respecting the patient-psychotherapist relationship.<sup>5</sup>

The current balancing test used by mental health professionals is problematic. No standard or clear rule is in place, causing inconsistencies in actions taken by psychotherapists. For instance, some mental health professionals may proceed with caution and refuse to disclose anything for fear of violating privacy laws, while others may fear upsetting or angering the requestor and may disclose certain information without proper verification or permission. Furthermore, the lack of federal regulation about this subject leaves mental health professionals questioning whether their decisions are lawful and in the best interests of all parties involved. To illustrate these problems, consider the following scenario:

Dr. Valerie Jones is a psychotherapist whose patient, Susan, recently died unexpectedly.<sup>6</sup> Susan was 65 years old when she came to see Dr. Jones for the first time ten months earlier and was experiencing major depressive symptoms. During the ten-month period of counseling, Dr. Jones held numerous sessions with Susan, compiling extensive and deeply personal notes during each session. One of the main topics discussed in Dr. Jones's sessions with Susan was the negative relationship Susan had with her 30-year-old daughter, as well as marital problems with her husband. Despite the poor relationship between Susan and her daughter, Susan's daughter was the one who urged Susan to begin seeking therapy.

The details surrounding Susan's death are unclear. While law enforcement and the family are unsure as to whether it was a suicide, the facts indicate that suicide is a possible cause of death. Susan's husband and daughter called Dr. Jones to notify her of Susan's death and are now requesting to see the psychotherapy notes from Susan's sessions. Because Susan died without either consenting or objecting to her husband and daughter seeing her psychotherapy notes, Dr. Jones must decide whether disclosure is appropriate.

The above dilemma highlights a problem for mental health professionals in the United States and raises a number of unanswered questions. Is Dr. Jones obligated to protect the privacy of Susan and prioritize the confidential relationship created between mental health

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5. Bonnie R. Benitez, *Confidentiality and its Exceptions (Including the US Patriot Act)*, THERAPIST, [https://www.camft.org/images/PDFs/AttorneyArticles/Bonnie/Confidentiality\\_and\\_its\\_Exceptions.pdf](https://www.camft.org/images/PDFs/AttorneyArticles/Bonnie/Confidentiality_and_its_Exceptions.pdf) (last updated June 2012).
  6. This is a hypothetical case that is based on anecdotal evidence.

professionals and patients? Under the Privacy Rule, is Dr. Jones permitted to disclose her notes to Susan's husband and daughter if they qualify as family members or personal representatives? Do mental health professionals' disclosing rights change when personal representatives or family members want access to the notes to pursue wrongful death claims in situations where the patient committed suicide? Finally, should psychotherapy notes be protected forever or become disclosable after a certain number of years after the patient's death?

Answering these questions requires textual interpretation of the Privacy Rule, research into the regulatory history of the Privacy Rule, and policy considerations. This Note attempts to answer these questions by providing recommendations to change certain provisions of the Privacy Rule to (1) strengthen the protection of psychotherapy notes and (2) provide clearer instruction to mental health professionals as to the disclosures of psychotherapy notes of deceased patients.

Part I discusses the background of HIPAA and the Privacy Rule, how the Privacy Rule defines psychotherapy notes, and disclosure rights of psychotherapy notes of deceased individuals under the Privacy Rule. Part II analyzes three ambiguous provisions under the privacy rule: the personal representative provision, the family member provision, and the 50-year provision. Part III discusses policy reasons for supporting heightened protection of psychotherapy notes of deceased individuals. Part IV analyzes disclosure rights of psychotherapy notes when a patient commits suicide and discusses certain considerations of mental health professionals in those situations. Part V explores relevant exceptions to disclosures of psychotherapy notes of deceased persons and reasons why the exceptions support greater protection for psychotherapy notes. Part VI is a brief summary of the current disclosure rights of psychotherapists regarding deceased patient's psychotherapy notes. Lastly, Part VII provides recommendations that the Department of Health and Human Services make changes to the Privacy Rule to explicitly provide greater protection for psychotherapy notes of deceased patients.

## I. BACKGROUND

### A. HIPAA and the Privacy Rule

Before Congress enacted HIPAA, the United States had no uniform medical data security standards or requirements that protected health information in the health care industry.<sup>7</sup> In the early 1990's the health care industry began incorporating electronic processes by converting from paper to computer-based patient records and electronic health records.<sup>8</sup> This transformation to electronic systems prompted a need for privacy regulations. In response, Congress enacted HIPAA on August 21, 1996, with the focus on “‘privacy, efficiency and modernization’ of health information.”<sup>9</sup> Despite the comprehensive health care law, Congress never expressly enacted any privacy legislation within HIPAA, so the U.S. Department of Health and Human Services (HHS) developed and published the HIPAA Privacy Rule.<sup>10</sup>

The Privacy Rule is a set of federal regulations under HIPAA.<sup>11</sup> The regulations establish national standards that protect individuals’ health information by addressing uses and disclosures of Protected Health Information (PHI), including psychotherapy notes.<sup>12</sup> PHI is “individually identifiable health information”<sup>13</sup> which includes demographic information, that “[i]s created or received by a health care provider, health plan, employer, or health care clearinghouse;” and:

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7. *Summary of the HIPAA Security Rule*, U.S. DEP’T HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html> (last visited July 26, 2013).
  8. See Deborah Kohn, *The Evolution of EHRs*, FOR RECORD (Oct. 2014), <http://www.fortherecordmag.com/archives/1014p10.shtml> (explaining that development of EHR systems began with the rise of the internet in the early 1990s).
  9. *In What Year Was HIPAA Passed into Legislature?*, HIPAA J. (Nov. 13, 2017), <https://www.hipaajournal.com/year-hipaa-passed-into-legislature/>; *Evenson v. Hartford Life & Annuity Ins. Co.*, 244 F.R.D. 666, 667 (M.D. Fla. 2007).
  10. *Summary of the HIPAA Privacy Rule*, U.S. DEP’T HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html?language=en> (last visited July 26, 2013).
  11. *The Privacy Rule: A Primer for Psychologists*, AM. PSYCHOL. ASS’N PRAC. ORG., at 2 (July 2013), available at <http://www.apapracticecentral.org/business/hipaa/hipaa-privacy-primer.pdf>.
  12. See *Uses and Disclosures of Protected Health Information: General Rules*, 45 C.F.R. § 164.502 (2013).
  13. 45 C.F.R. § 160.103 (2013).

- “[r]elates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual;”
- that identifies the patient or could reasonably be used to identify the individual; and
- that is transmitted or maintained in any form or medium.<sup>14</sup>

Examples of PHI include name, address, phone number, email address, Social Security Number, medical record number, or “[a]ny other characteristic that could uniquely identify the individual.”<sup>15</sup>

The Privacy Rule also delineates patients’ rights regarding access to their PHI.<sup>16</sup> For example, absent exceptional circumstances, a patient “has a right of access to inspect and obtain a copy of [PHI] about the [patient] in a designated record set, for as long as the [PHI] is maintained in the designated record set.”<sup>17</sup> If a state privacy law gives the patient greater access rights than the Privacy Rule, the state law trumps the Privacy Rule.<sup>18</sup> The Privacy Rule applies to “covered entities,” which include health plans, health care clearinghouses, any health care providers, and their business associates.<sup>19</sup> Covered mental health professionals include psychologists, psychiatrists, and clinical social workers.<sup>20</sup>

*B. The Privacy Rule and Psychotherapy Notes*

Despite patients’ right to access their individual PHI, the Privacy Rule limits patient rights to access and inspect their psychotherapy notes in two distinct ways. First, patients do not have a right that

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14. *Id.*

15. *Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule*, DUKE U. CAMPUS INST. REV. BOARD, <https://campusirb.duke.edu/irb-policies/health-insurance-portability-and-accountability-act-hipaa-privacy-rule> (last visited Dec. 19, 2018).

16. U.S. DEP’T HEALTH & HUM. SERV., *supra* note 10.

17. 45 C.F.R. § 164.524(a) (2014).

18. AM. PSYCHOL. ASS’N PRAC. ORG., *supra* note 11, at 4.

19. 45 C.F.R. § 160.103 (2013).

20. *HIPAA Helps Caregiving Connections*, U.S. DEP’T HEALTH & HUM. SERV., 1 (2015), available at <https://www.hhs.gov/sites/default/files/hipaa-helps-prevent-harm.pdf?language=es>.

guarantees access to their own psychotherapy notes.<sup>21</sup> Second, when a mental health professional denies a patient's access to the psychotherapy notes, the denial is not subject to a review process, as it is with other records.<sup>22</sup> When a patient requests PHI other than psychotherapy notes, the patient normally "has a right to have the denial reviewed by a licensed health care professional designated by the covered entity who did not participate in the original decision to deny."<sup>23</sup>

Psychotherapy notes are: notes that have been recorded (by any means); by a mental health professional who is providing health care services; recording or scrutinizing a conversation that occurred at a private, group, or family counseling session; and are not included with the participants' medical records.<sup>24</sup> Psychotherapy notes do not include: "medication prescription and monitoring, counseling session start and stop times, the modalities and frequencies of treatment furnished, results of clinical tests," summaries of "[d]iagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date,"<sup>25</sup> and any information that is in a patient's medical record.<sup>26</sup>

There are two main reasons why psychotherapy notes are considered more private than other PHI. First, psychotherapy notes typically contain especially sensitive information.<sup>27</sup> Often, patients go to psychotherapy to bare their souls and take comfort in knowing that the information they reveal is confidential.<sup>28</sup> Therefore, psychotherapy notes deserve greater privacy protections from the perspective of the patients.

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21. Access of Individuals to Protected Health Information, 45 C.F.R. § 164.524(a)(1)(i) (2014).
  22. 45 C.F.R. § 164.524(a)(2)(i) (2014).
  23. *Individuals' Right Under HIPAA to Access their Health Information* 45 CFR § 164.524, U.S. DEP'T HEALTH & HUMAN SERV., <https://www.hhs.gov/hipaa/forprofessionals/privacy/guidance/access/index.html> (last updated Feb. 25, 2016).
  24. 45 C.F.R. § 164.501 (2013).
  25. *Id.*
  26. *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, *supra* note 2.
  27. *Id.*
  28. *Protecting Your Privacy: Understanding Confidentiality*, AM. PSYCHOL. ASS'N, <http://www.apa.org/helpcenter/confidentiality.aspx> (last visited Jan. 10, 2018).



Second, psychotherapy notes are not necessary for treatment, payment, or health care operations purposes.<sup>29</sup> Rather, they are the mental health professional's personal notes.<sup>30</sup> Psychotherapy notes are often used to help the provider recall details of the therapy sessions, list hunches or hypotheses to explore further, and write questions for future sessions.<sup>31</sup> A commonly used documentation format among psychotherapists is a SOAP Note.<sup>32</sup> During a session, a mental health professional records (1) a **S**ubjective analysis of how the client describes the problem; (2) an **O**bjective analysis of what the mental health professional observes about the client; (3) an **A**ssessment of the mental health professional's impressions of the client; and (4) a future **P**lan for the client. While psychotherapy notes are used by many mental health professionals, they are not required to be readable by anyone else but the originator.<sup>33</sup> If a mental health professional does take notes, state law governs the required retention period for psychotherapy notes.<sup>34</sup> Therefore, because of both the sensitive and personal nature of psychotherapy notes, the heightened privacy protection serves the interests of not only the patients, but also of mental health professionals.

*C. The Privacy Rule and Disclosure of Psychotherapy Notes of Deceased Individuals*

Under the Privacy Rule, the duty of confidentiality continues after the patient's death.<sup>35</sup> Similarly, the patient-psychotherapist privilege

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29. *Id.*; for definitions of treatment, payment, and health care operations, see 45 C.F.R. § 164.501 (2013).
30. *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, *supra* note 2.
31. Howard Spector, *Progress Note or Psychotherapy Notes: Are You Sure You Know the Difference?*, SIMPLEPRACTICE (Oct. 2, 2014), <https://www.simplepractice.com/blog/progress-note-or-psychotherapy-note-are-you-sure-you-know-the-difference/>.
32. Tamara Suttle, *How to Take Clinical Notes Using SOAP*, <http://tamarasuttle.com/how-to-take-clinical-notes-using-soap/> (last visited Sept. 9, 2018).
33. Spector, *supra* note 31.
34. Kristen Lambert & Moira Wertheimer, *Retaining Patients' Psychiatric Records*, PSYCHIATRIC NEWS (Mar. 2, 2016), <https://psychnews.psychiatryonline.org/doi/10.1176/appi.pn.2016.3a.20>.
35. James Orlando, *Disclosure of Deceased Person's Medical Records*, OLR RESEARCH REPORT (Feb. 13, 2013), <https://www.cga.ct.gov/2013/rpt/2013-R-0124.htm>.

survives the patient's death.<sup>36</sup> Effective psychotherapy is dependent upon the privilege surviving death because if this were not the case, individuals would know that what they shared in psychotherapy could be disclosed immediately after their death. As a result, patients would likely be reluctant to fully disclose their thoughts and feelings in psychotherapy or choose to not attend psychotherapy at all.

There are various provisions under the Privacy Rule that address disclosing records of deceased individuals. The problem, however, is that no provision within the Privacy Rule clarifies conditions for the disclosure of psychotherapy notes of deceased patients. To better understand how and to whom psychotherapy notes of deceased patients may be disclosed under the Privacy Rule, it is important to analyze the existing provisions concerning disclosure of a deceased individual's records. The analysis must take into consideration the rights and interests of the mental health professional, the deceased patient, and the person requesting the information.

## II. ANALYSIS OF CURRENT PRIVACY RULE PROVISIONS: PERSONAL REPRESENTATIVE, FAMILY MEMBER, AND 50-YEAR PROVISION

### A. *Personal Representative's Right to Access Psychotherapy Notes Under the Privacy Rule*

The Privacy Rule states, “[i]f under applicable law an executor, administrator, or other person has authority to act on behalf of a deceased individual or of the individual's estate, a covered entity must treat such person as a personal representative . . . with respect to [PHI] relevant to such personal representation.”<sup>37</sup> Because the Privacy Rule never specifically says whether an executor or administrator of the deceased individual's estate is the personal representative, mental health professionals must look at their state laws to determine who qualifies as a personal representative.<sup>38</sup> If an individual dies without naming a personal representative, state law determines by default who serves in this capacity.<sup>39</sup>

Proponents of disclosure may argue that personal representatives can access psychotherapy notes because the Privacy Rule does not expressly exclude psychotherapy notes in the personal representative

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36. Leslie, *supra* note 3.

37. 45 C.F.R. § 164.502(g)(4) (2013).

38. *Disclosing Deceased Patient's PHI Without Authorization*, HIPAA SEC. & PRIVACY STAFF TRAINER, at 2 (Aug. 2004), <http://www.hcpro.com/content/42703.pdf>.

39. Dimick, *supra* note 1.

provision.<sup>40</sup> The fact that HHS did not exclude psychotherapy notes in the provision arguably means that HHS intended for personal representatives to have access to psychotherapy notes in certain circumstances.

For a number of reasons, however, psychotherapy notes are not disclosable to personal representatives nor do personal representatives have disclosure rights under the Privacy Rule. The Privacy Rule instructs that mental health professionals are required to treat an individual's personal representative as the deceased individual with respect to uses and disclosures of the deceased's PHI.<sup>41</sup> The Privacy Rule states that an individual has a right to access, inspect, and obtain a copy of their PHI except for psychotherapy notes.<sup>42</sup> Therefore, because individuals are not guaranteed the right to access their own psychotherapy notes when they are alive, personal representatives cannot access the deceased individual's notes either.

There is an argument that even though personal representatives cannot themselves access deceased patients' psychotherapy notes, they can authorize disclosure of the notes to others. The Privacy Rule expressly states that, except for specific, limited circumstances, mental health professionals "must obtain an authorization for any use or disclosure of psychotherapy notes."<sup>43</sup> Because the Privacy Rule permits the personal representative the same access rights that the deceased individual had,<sup>44</sup> and individuals can authorize disclosure of their own psychotherapy notes to other people,<sup>45</sup> arguably, the personal representative also has a right to authorize disclosure of the deceased individual's notes.

HHS could not possibly have intended for personal representatives to be able to disclose psychotherapy notes to anyone. This type of disclosure would defeat the purpose of having heightened protection for psychotherapy notes after death because the notes could be easily disclosable to anyone as long as the personal representative authorizes disclosure.

Furthermore, textual interpretation of an additional Privacy Rule provision does not support personal representatives being able to disclose psychotherapy notes to anyone. The Privacy Rule states that

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40. *Compare* 45 C.F.R. § 164.502(g)(4), *with* 45 C.F.R. § 164.502(g)(4), *with* 45 C.F.R. § 164.524(a)(1) (2013) (excluding psychotherapy notes from the provision).
  41. 45 C.F.R. § 164.502(g)(1) (2013).
  42. 45 C.F.R. § 164.524(a)(1)(i) (2014).
  43. 45 C.F.R. § 164.508(a)(2) (2013).
  44. 45 C.F.R. § 164.524(a)(1)(i) (2014).
  45. 45 C.F.R. § 164.508(a)(2) (2013).

personal representatives only have rights to the deceased individual's PHI "relevant to such personal representation."<sup>46</sup> To understand whether this ambiguous phrase permits the personal representative to ever disclose the deceased patient's notes to other people, it is important to look at the duties and responsibilities of a personal representative. The basic responsibilities of personal representatives are: (1) to identify and take control of the decedent's assets; (2) pay creditors; (3) pay taxes; (4) locate heirs; and (5) distribute assets and close the estate.<sup>47</sup> An additional responsibility may occur in situations where the patient commits suicide. In such cases, a personal representative has authority to file a wrongful death claim on behalf of the estate, claiming that the mental health professional was negligent in failing to prevent the suicide.<sup>48</sup>

An analysis of each of these responsibilities reveals that personal representatives do not have a right to authorize disclosure of the deceased individual's psychotherapy notes. First, a personal representative identifies and collects assets of the estate by creating inventory reports that include any property of value owned by the deceased at death and any unpaid amounts due to the deceased such as interest and dividends.<sup>49</sup> The deceased's psychotherapy notes are not going to contain any information relevant to this task. Second, psychotherapy notes will not need to be disclosed to personal representatives to pay the deceased's creditors and taxes. The personal representative will look to documents such as claims filed by creditors and tax returns of the deceased,<sup>50</sup> rather than psychotherapy notes. Third, psychotherapy notes do not need to be released to locate heirs because there are already procedures in place through state intestacy laws for how personal representatives should fulfill this responsibility.<sup>51</sup>

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46. 45 C.F.R. § 164.502(g)(2) (2013).

47. *See, e.g.*, OHIO REV. CODE ANN. § 2113.31 (West 2012); N.M. STAT. ANN. §§ 45-3-705, 45-3-706 (2018); COLO. REV. STAT. §§ 15-12-705, 15-12-706 (2015); ALASKA PROB. PROP. R. 7 (LEXIS 2018).

48. *See, e.g.*, ARIZ. REV. STAT. ANN. § 12-612 (2015); OHIO REV. CODE ANN. § 2125.02 (West 2017); CAL. CIV. PROC. CODE § 377.60 (West 2005); N.Y. EST. POWERS & TRUSTS L. § 5-4.1 (McKinney 2003).

49. *See Closing and Distributing the Probate Estate*, SUPERIOR CT. CAL., [http://www.sccscourt.org/self\\_help/probate/property/closing\\_distributing.shtml](http://www.sccscourt.org/self_help/probate/property/closing_distributing.shtml) (last visited Feb. 16, 2018).

50. *See id.*

51. *See* William Hussey, Jr., *Personal Representatives and Fiduciaries: Executors, Administrators and Trustees and Their Duties*, WHITE & WILLIAMS, <https://www.whiteandwilliams.com/resources-alerts-Personal-Representatives-and-Fiduciaries-Executors-Administrators-and-Trustees-and-Their-Duties.html> (last visited Jan. 5, 2018).

Only in rare circumstances would psychotherapy notes potentially contain information about an unknown heir that would be useful information for the personal representative. The disadvantages of releasing the psychotherapy notes, such as exposure of other sensitive information and violating confidentiality, outweigh the unlikely possibility of actually finding an unknown heir of the deceased. Additionally, distributing assets to the various beneficiaries and closing the estate by filing a closing statement with the court do not require information that would be disclosed within psychotherapy notes.<sup>52</sup>

Finally, personal representatives have the authority to file a wrongful death claim on behalf of the estate if the patient committed suicide and the mental health professional was negligent. However, the Privacy Rule currently does not permit personal representatives to access psychotherapy notes for any purpose because they are subject to the same restrictions as the patients they represent, and patients cannot access their own psychotherapy notes.<sup>53</sup> Furthermore, state law determines who has authority to bring wrongful death claims,<sup>54</sup> so it would contradict state law if personal representatives were allowed to authorize another person to bring a wrongful death claim and have access to the notes.

Therefore, under the Privacy Rule, personal representatives do not have a right to access psychotherapy notes themselves, nor do they have a right to authorize disclosure to anyone else. Unless patients give authorization for their mental health professional to disclose the notes to their personal representatives before they die, personal representatives have no right to access the psychotherapy notes.

*B. Family Member's Rights to Access Psychotherapy Notes Under the  
Privacy Rule*

1. Provision Background

On January 17, 2013, HHS expanded HIPAA by implementing provisions of the Health Information Technology for Economic and Clinical Health (HITECH) Act and released the final omnibus rule,

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52. See Dennis Masino, *Steps in Closing an Estate of a Decedent with Beneficiaries*, LEGALZOOM, <http://info.legalzoom.com/steps-closing-estate-decedent-beneficiaries-22052.html> (last visited Nov. 13, 2017).

53. 45 C.F.R. § 164.502(g)(4) (2013).

54. See, e.g., ARIZ. REV. STAT. ANN. § 12-612 (2015); OHIO REV. CODE ANN. § 2125.02 (West 2017); CAL. CIV. PROC. CODE § 377.60 (West 2005); N.Y. EST. POWERS & TRUSTS L. § 5-4.1 (McKinney 2003).

increasing privacy and security protections.<sup>55</sup> The final rule permitted mental health professionals to disclose PHI to a second group of people – family members, relatives, and others who had access to the deceased’s health information prior to death.<sup>56</sup> The reason that HHS proposed and then enacted this provision was because people expressed concerns that family members, relatives, and others were having difficulty accessing PHI after the death of the individual – even in situations where the requesting individual had access to the PHI prior to the patient’s death.<sup>57</sup> Family members and friends were having difficulty accessing the deceased individual’s PHI because they did not qualify as a personal representative under the personal representative provision of the Privacy Rule.<sup>58</sup>

## 2. Textual Interpretation

The Privacy Rule states that a mental health professional “may . . . disclose to a family member, other relative, or a close personal friend of the individual, or any other person identified by the individual, the [PHI] directly relevant to such person’s involvement with the individual’s health care or payment related to the individual’s health care”<sup>59</sup> “prior to the individual’s death.”<sup>60</sup> The Privacy Rule defines “family members” as “any person who is a first-degree, second-degree, third-degree, or fourth-degree relative of the individual or of a dependent of the individual.”<sup>61</sup> “First-degree relatives include parents, spouses, siblings, and children.”<sup>62</sup> Depending on the circumstances, “spouses, parents, children, domestic partner, other relatives, or friends” of the deceased could receive access to the notes as well.<sup>63</sup> Disclosures to relatives or friends are not required, so if a mental health professional either questions the relationship of the requesting person

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55. Jennifer Downs Burgar & Neil W. Hoffman, *HHS Releases Final HIPAA Omnibus Rule: A Summary of the Changes*, LEXOLOGY (Jan. 31, 2013), <https://www.lexology.com/library/detail.aspx?g=7196ed59-213b-4706-b8d2-03b66da32737>; see 45 C.F.R. § 164.510(b)(1) (2013); see also 45 C.F.R. § 164.510(b)(5) (2013).
56. Dimick, *supra* note 1.
57. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules, 78 Fed. Reg. 5566, 5614 (Jan. 25, 2013).
58. *Id.*; See 45 C.F.R. § 165.502(g)(4) (2013).
59. 45 C.F.R. § 164.510(b)(1)(i) (2013).
60. 45 C.F.R. § 164.510(b)(5) (2013).
61. 45 C.F.R. § 160.103 (2013).
62. *Id.*
63. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules, 78 Fed. Reg. at 5614.

or believes that disclosure of the deceased's PHI would not be appropriate, the mental health professional is not required to make the disclosure.<sup>64</sup> As long as the mental health professional uses her professional judgment to determine that disclosing the information is in the best interest of the patient, disclosure is permitted.<sup>65</sup>

The Privacy Rule imposes a limitation on PHI that family members and relatives may access. Mental health professionals are only permitted to disclose PHI "relevant to such person's involvement" with "the individual's care or payment for health care prior to the individual's death."<sup>66</sup> Consequently, to know whether family members or friends have access rights to a deceased individual's psychotherapy notes, it is important to determine whether such notes fall within the scope of this provision.

Textual interpretation of the family member provision does not support family members or friends having access rights. The final part of the provision, "payment related to the individual's health care," is fairly straightforward. For example, a family member is paying the patient's psychotherapy bills and the mental health professional discusses payment options or issues regarding the bill with the family member.<sup>67</sup> Another example is when a mental health professional may disclose billing information to a family member of the deceased patient who is assisting with closing the decedent's estate.<sup>68</sup> Payment information is not typically located within the psychotherapy notes because psychotherapy notes are not intended to be seen by, or communicated to, people besides the mental health professional.<sup>69</sup> For this reason, psychotherapists normally do not keep payment information in psychotherapy notes.

Even if a mental health professional does keep payment information within her psychotherapy notes, the Privacy Rule limits a third party's access to the notes only to the information related to payment.<sup>70</sup> Thus, family members would only have a right to access the relevant payment

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64. Dimick, *supra* note 1.

65. *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, *supra* note 2.

66. 45 C.F.R. § 164.510(b)(5) (2013).

67. HIPAA SEC. & PRIVACY STAFF TRAINER, *supra* note 38, at 2.

68. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules, 78 Fed. Reg. at 5614.

69. *See Your Medical Records*, U.S. DEP'T HEALTH & HUMAN SERV., <https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html> (last reviewed June 16, 2017).

70. *See* 45 C.F.R. § 164.510(b)(5) (2013).

information. No potential confidentiality issues would arise from permitting access to view the payment-related information.

Also, family members and relatives should never have a right to access the psychotherapy notes for insurance purposes because insurance companies are prohibited from requiring patients to authorize disclosure of their records as a condition for treatment, eligibility for benefits, or payment of claims.<sup>71</sup> The support for this intent is strengthened by the provision that “health insurers cannot require [patients] to turn over psychotherapy notes during an audit of [the patient’s] record.”<sup>72</sup> Because of these access restrictions imposed on insurance companies, family members or friends will not need access to the psychotherapy notes to provide them to insurance companies. Therefore, under the Privacy Rule, family members or friends do not have access rights to psychotherapy notes because of the person’s involvement with “payment related to the individual’s health care.”

But what about access rights for family members or friends because of “such person’s involvement with the individual’s health care?” Again, textual interpretation of this part of the provision does not support the argument that family members or friends have access to the notes. HHS is silent about whether psychotherapy notes are disclosable under this provision, but the department has released examples illustrating how relatives, friends, or other people can be involved in a patient’s health care. A HIPAA training guideline stated, “a pregnant patient may bring her husband into the treatment room when visiting her obstetrician,”<sup>73</sup> and in this scenario, the physician may disclose to the husband PHI about the wife’s current health status and treatment.<sup>74</sup> Another example is that a “health care provider could describe the circumstances that led to an individual’s passing with the decedent’s sister who is asking about her sibling’s death.”<sup>75</sup> Here the physician could explain that the patient died of a heart attack or complications from surgery.<sup>76</sup> But, in any scenario where covered entities are permitted to disclose

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71. AM. PSYCHOL. ASS’N PRAC. ORG., *supra* note 11, at 6.

72. *Id.*

73. HIPAA SEC. & PRIVACY STAFF TRAINER, *supra* note 38.

74. *Id.*

75. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules, 78 Fed. Reg. at 5614.

76. *Does the HIPAA Privacy Rule Permit a Doctor to Discuss a Patient’s Health Status, Treatment, or Payment Arrangements with the Patient’s Family and Friends?*, U.S. DEP’T HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/faq/488/does-hipaa-permit-a-doctor-to-discuss-a-patients-health-status-with-the-patients-family-and-friends/index.html> (last reviewed July 26, 2013).



PHI to family members or friends, they must use their personal judgment to disclose only the minimum necessary to accomplish the intended purpose.<sup>77</sup>

The above examples are outside the mental health care context, but they are helpful in providing a better understanding of what a “person’s involvement with the individual’s health care” means. Psychotherapy sessions are different from other types of medical appointments because of their intense nature of privacy. Unlike other types of medical appointments where patients may be much more willing to permit family or friends to join them in their appointment, psychotherapy happens behind closed doors in an intimate and private environment. The health care involved in psychotherapy happens between the mental health professional and the patient, no one else.

Proponents for disclosure may argue that there are ways family members or friends are involved with the individual’s health care. Returning to the hypothetical in the Introduction will help illustrate the extent that family or friends are often involved in an individual’s psychotherapy:

Dr. Jones had weekly sessions with Susan for ten months prior to Susan’s death. For almost every session, Susan’s husband drove Susan to and from Dr. Jones’s office. While Susan never told him in detail what she talked about in the sessions, Susan’s husband wanted to show his support by taking her to the therapy sessions. After Susan died, Susan’s husband requested to see the notes, as he believes he is entitled to their access because he was a part of her treatment and care as her driver.

Susan’s husband does not have access to the psychotherapy notes despite his argument that he was involved in Susan’s health care prior to her death. HIPAA training guidelines mention an example where a patient’s coworker drives an injured patient to and from the emergency room after suffering an injury at work.<sup>78</sup> The guidelines state that in the above example, health care professionals may disclose limited PHI to the coworker, such as the patient’s current condition or status, because the coworker *is* involved in the patient’s current health care by bringing the patient to the hospital.<sup>79</sup> This limited PHI that can be disclosed is not found in psychotherapy notes, but in the medical

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77. 45 C.F.R. § 164.502(b) (2013).

78. *Disclosing PHI to Relatives, Friends, or Others Involved in a Patient’s Care*, HIPAA SEC. & PRIVACY STAFF TRAINER (Mar. 2004), <http://www.hcpro.com/content/42698.pdf>.

79. *Id.*

chart.<sup>80</sup> So, despite Susan's husband's involvement in her care as her driver, he cannot access her psychotherapy notes because the psychotherapy notes are separate from the medical chart.

There is also an argument that while driving a person to and from psychotherapy appointments does not qualify as being involved in the patient's care, helping the patient take medications prescribed by a psychotherapist may. Even this argument fails because psychotherapy notes exclude anything relating to medication prescription and monitoring.<sup>81</sup>

Finally, just as with personal representatives, there is a question of whether a family member or friend can access the psychotherapy notes for purposes of filing a wrongful death claim. In instances where no personal representative is named prior to death, the personal representative typically defaults to a family member<sup>82</sup> and that person will be the one to pursue a wrongful death claim. As discussed earlier, however, the Privacy Rule does not give the personal representative a right to access the deceased individual's psychotherapy notes. In situations where family members do not qualify as the personal representative under the provision of the Privacy Rule but wish to access the notes to pursue a wrongful death claim, the family member provision prohibits their access as well. The family member provision expressly states that the relevant PHI must be related to health care or payment of care *prior to the individual's death*.<sup>83</sup> Accessing the notes to pursue a wrongful death claim happens after the patient's death, and therefore, family members or friends cannot access the notes for wrongful death claim purposes.

As in the case of the personal representative provision, if the patient authorized a family member or friend to have access to the notes before the patient died, the family member or friend has access to the notes through the authorization of the patient.<sup>84</sup> Without such authorization, however, family members or friends have no access rights to a deceased individual's psychotherapy notes under the Privacy Rule.

### C. 50-Year Provision

In addition to the family member provision, HHS amended the Privacy Rule by limiting the period for which covered entities must protect PHI after a patient's death.<sup>85</sup> A covered entity may now disclose

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80. See 45 C.F.R. § 164.501 (2013).

81. *Id.*

82. Dimick, *supra* note 1.

83. 45 C.F.R. § 164.510(b)(5) (2013).

84. See 45 C.F.R. § 164.508(a)(2) (2013).

85. See 45 C.F.R. § 164.502(f)

PHI of a deceased individual to anyone fifty years after the death of the individual.<sup>86</sup> One primary purpose of this provision is to protect privacy interests of both the deceased individual and family members and other individuals with a relationship to the decedent.<sup>87</sup> With the fifty-year time period, approximately two generations have passed since the death of the patient.<sup>88</sup> HHS felt that fifty years was enough time to protect the privacy interests of the living relatives, even if the records included highly sensitive information like HIV/AIDS status or psychiatric or substance abuse treatment.<sup>89</sup>

Another purpose for permitting disclosure after fifty years is to allow access to the records for historical purposes.<sup>90</sup> Before this amendment, archivists, biographers, and historians expressed frustration to HHS about the lack of access to old medical records.<sup>91</sup> HHS proposed fifty years “to balance the privacy interests of living relatives or other affected individuals with a relationship to the decedent, with the difficulty of obtaining authorizations from personal representatives as time passes.”<sup>92</sup>

In response to the proposed final rule, some commenters expressed concern about limiting the period of protection for psychotherapy notes, arguing that there should be no limit on protection of those notes.<sup>93</sup> Ultimately, HHS decided not to create an exception for psychotherapy notes in the 50-year provision.<sup>94</sup> The department reasoned that states may enact stricter laws that would provide greater protection and the Privacy Rule would not override or interfere with such state laws.<sup>95</sup>

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86. *Id.*

87. *Health Information of Deceased Individuals*, U.S. DEP'T HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/health-information-of-deceased-individuals/index.html> (last reviewed Sept. 19, 2013).

88. Period of Protection for Decedent Information, 78 Fed. Reg. 17, 5613-14 (Jan. 23, 2013) (to be codified at 45 C.F.R. 164.502(f)).

89. *Id.*

90. *Id.*

91. *Id.* at 5613-14.

92. *Id.* at 5614.

93. *Id.*

94. *See* 45 C.F.R. § 164.502(f) (2013).

95. Period of Protection for Decedent Information, 78 Fed. Reg. 17, 5613-14 (Jan. 23, 2013) (to be codified at 45 C.F.R. 164.502(f)).

### III. POLICY REASONS FOR NOT DISCLOSING PSYCHOTHERAPY NOTES

There are a number of policy reasons that support creating federal regulations that provide higher levels of protection for psychotherapy notes than for other PHI. First, if individuals feel that the sensitive information they tell their mental health professionals will not be kept confidential after death, they may choose to not seek help.<sup>96</sup> Furthermore, even if individuals decide to attend psychotherapy, they may not feel comfortable telling their psychotherapist revealing and sensitive information because they fear that their information will not be kept confidential.<sup>97</sup> If patients do not feel comfortable sharing information, they will not speak openly about their issues and psychotherapy will not be an effective form of treatment.<sup>98</sup> Therefore, not seeking mental health help, or receiving ineffective mental health treatment resulting from individuals' lack of confidence in privacy, ultimately harms society and can have devastating effects on people's health.

The negative consequences discussed above are not hypothetical. In the United States, mental illness carries a stigma that limits access to care and discourages people from seeking mental health treatment.<sup>99</sup> A study in 2011 found that only 59.6% of individuals with a mental illness – including conditions like anxiety, depression, schizophrenia, and bipolar disorder – reported receiving treatment.<sup>100</sup> In addition to stigma, fear that information will not be kept private is already another top reason why Americans do not seek mental health help.<sup>101</sup> Therefore, in

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96. David Susman, *8 Reasons Why People Don't Get Treatment for Mental Illness*, MENTAL HEALTH WELLNESS BLOG (June 11, 2015), <http://davidsusman.com/2015/06/11/8-reasons-why-people-dont-get-mental-health-treatment/>.
97. *Protecting Your Privacy: Understanding Confidentiality*, *supra* note 28.
98. Jared DeFife, *Five Tips on How to Talk About Yourself in Therapy*, PSYCHOL. TODAY (Mar. 29, 2011), <https://www.psychologytoday.com/blog/the-shrink-tank/201103/five-tips-how-talk-about-yourself-in-therapy>.
99. Patrick W. Corrigan et al., *The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care*, 15 PSYCHOL. SCI. PUB. INT., Oct 2014, at 37, 40 (discussing stigmas that affect care seeking in America).
100. *Id.*
101. See Loren Soeiro, *10 Reasons Why People Refuse to Talk to Therapists*, PSYCHOL. TODAY (Oct. 23, 2017), <https://www.psychologytoday.com/blog/i-hear-you/201710/10-reasons-why-people-refuse-talktherapists>.

order for individuals to feel comfortable going to therapy and speaking openly in their sessions, stricter regulations that protect people's confidential information are necessary.

Disclosing psychotherapy notes of deceased patients could lead to another negative consequence – harming the family members or friends that access the notes.<sup>102</sup> For instance, returning again to the hypothetical from the Introduction:

During Susan's counseling sessions with Dr. Jones, Susan talked a lot about her relationship with her daughter and husband. Susan disclosed information about how she resented her husband and daughter because she was only seventeen when she had her daughter. She discussed feelings of despair about the way her life turned out. Because of religious beliefs, she was forced to marry and have the child. Susan spoke honestly and openly about how she wished she never had met her husband or had her daughter. Susan expressed these feelings to Dr. Jones, believing that they would always be confidential.

If Dr. Jones were to give Susan's psychotherapy notes to Susan's husband, the information they contained could be damaging to both the daughter's and husband's mental health.

Susan's husband, who genuinely loved his wife, may feel responsible for her depression or feel as though he was the one to force her into the marriage and was thus responsible for her suicide, possibly developing depressive symptoms of his own. Even though they had their difficulties, Susan's daughter was the one to encourage Susan to seek therapy, making it clear that she does care for her mother. If she finds out that she was never wanted and was a source of her mother's unhappiness, she may similarly begin to exhibit depressive symptoms or grow bitter toward her mother's memory. The above scenario illustrates how prohibiting access rights to the deceased individual's notes potentially prevents additional harm to family and friends.

A final negative consequence is that disclosing the psychotherapy notes may also harm the deceased patient. Disclosing the notes may result in harming the patient by tainting the patient's reputation.<sup>103</sup> For example, assume a deceased patient's psychotherapy notes reveal information about infidelity. If those notes are disclosed to relatives upon the patient's death, the patient's loved ones may drastically

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102. MARLENE M. MAHEU ET AL., THE MENTAL HEALTH PROFESSIONAL AND THE NEW TECHNOLOGIES: A HANDBOOK FOR PRACTICE TODAY 231 (2005).

103. *Does Patient Confidentiality End with Death? Depends on Definition of Person*, RELIAS (Sept. 1, 2007), <https://www.ahcmedia.com/articles/106005-does-patient-confidentiality-end-with-death-depends-on-definition-of-person>.

change their opinion of the deceased. This matters because, again, people will be more willing to seek and engage in therapy knowing that what they say will be protected after death.

#### IV. CONSIDERATIONS FOR PATIENTS WHO COMMIT SUICIDE

Mental health professionals have additional concerns with regards to disclosing psychotherapy notes if their patient commits suicide. Returning to the hypothetical in the Introduction will help illustrate the dilemma for mental health professionals.

Dr. Jones, Susan's psychotherapist, finds out that Susan committed suicide. Knowing that Susan had been seeking counseling, Susan's daughter and husband contact Dr. Jones asking to see Susan's psychotherapy notes. Susan's family is requesting the notes hoping to gain more insight as to why Susan committed suicide. They feel that knowing this information will help give them closure about her sudden and unexpected death. Additionally, Susan's husband is upset his wife's counseling failed and wants to see if the notes contained any information that would help support a wrongful death claim.

Dr. Jones is devastated to hear that Susan is dead and is uncertain about whether she has any obligation to disclose the notes. Dr. Jones's primary concern is to preserve Susan's privacy and uphold the confidential relationship she established with Susan as her psychotherapist. There are potential benefits to releasing the notes such as giving Susan's family insight into why she committed suicide and providing closure for the family. Dr. Jones has concerns, however, about disclosing the notes to Susan's family because she knows that the notes contain harmful information – information that could damage Susan's reputation and the mental health of Susan's husband and daughter. Furthermore, Dr. Jones does not want to voluntarily hand over Susan's notes and assist her family in bringing a possible wrongful death claim against her.

Suicide is the number one reason lawsuits are brought against mental health professionals.<sup>104</sup> While statistics vary, roughly twenty-five percent of psychologists lose a client to suicide in their careers and the number rises to fifty percent for psychiatrists whose patients are

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104. Sulome Anderson, *How Patient Suicide Affects Psychiatrists*, ATLANTIC (Jan. 20, 2015), <https://www.theatlantic.com/health/archive/2015/01/how-patient-suicide-affects-psychiatrists/384563/>.

typically more severely troubled.<sup>105</sup> The reason that mental health professionals may be held liable for wrongful death is for “failure to recognize patient’s suicidal tendencies and not taking precautionary measures to protect the patient.”<sup>106</sup> Both the emotional and potential legal burden of treating suicide patients disincentivizes many mental health professionals from agreeing to treat suicidal patients.<sup>107</sup>

Each state has its own wrongful death statute,<sup>108</sup> which establishes procedures for bringing wrongful death actions. Generally, a successful wrongful death cause of action requires proof of the following elements:

- The death of a human being;
- Caused by another’s negligence, or with intent to cause harm;
- The survival of family members who are suffering monetary injury as a result of the death; and
- The appointment of a personal representative for the decedent’s estate.<sup>109</sup>

For an individual to pursue a wrongful death claim against a mental health professional, the individual would need the psychotherapy notes to investigate whether a cause of action exists. Without the notes, the individual would be unable to gain relevant and necessary information needed to initiate a wrongful death claim. On the other hand, disclosing the notes risks exposing confidential information and violating the patient-psychotherapist privilege.

As previously discussed, under the current Privacy Rule, personal representatives and family members cannot access psychotherapy notes of a deceased individual to pursue a wrongful death claim. This is

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105. Tori DeAngelis, *Coping with A Client’s Suicide*, AM. PSYCHOL. ASS’N GRADPSYCH MAG. (Nov. 2008), <https://www.apa.org/gradpsych/2008/11/suicide.aspx>.

106. David A. Jobes & Alan L. Berman, *Suicide and Malpractice Liability: Assessing and Revising Policies, Procedures, and Practice in Outpatient Settings*, 24 PROF. PSYCHOL.: RES. & PRAC. 91, 92 (1993).

107. Anderson, *supra* note 105.

108. ELIZABETH M. KING & JAMES P. SMITH, COMPUTING ECONOMIC LOSS IN CASES OF WRONGFUL DEATH v (1988).

109. *See, e.g.*, OHIO REV. CODE ANN. §2125.01 (West 2017); N.Y. EST. POWERS & TRUSTS L. § 5-4.1 (McKinney 2003); ARIZ. REV. STAT. ANN. § 12-612 (2015); CAL. CIV. PROC. CODE § 377.60 (West 2005).

problematic because it prevents people wanting to pursue wrongful death claims from seeking adequate legal remedies.

## V. ANALYSIS OF RELEVANT EXCEPTIONS IN THE PRIVACY RULE

Under 45 C.F.R. § 164.508(a)(2)(ii), the Privacy Rule lists a number of exceptions that explicitly permit mental health professionals to disclose psychotherapy notes without authorization from the patient or personal representative.<sup>110</sup> First, “[a] covered entity may disclose [psychotherapy notes] to a coroner or medical examiner for the purpose of identifying a deceased person, determining a cause of death, or other duties as authorized by law.”<sup>111</sup>

Second, a covered entity may disclose PHI about an individual who has died to law enforcement officials.<sup>112</sup> The purpose behind this exception is to alert law enforcement to the death of the individual if the covered entity has a suspicion that such death may have resulted from criminal conduct<sup>113</sup> or to determine whether the death was a result of suicide.<sup>114</sup> Finally, “[a] covered entity may disclose [PHI] to funeral directors, consistent with applicable law, as necessary to carry out their duties with respect to the decedent.”<sup>115</sup> So, only in limited cases when a patient discusses information relating to funeral arrangements with her psychotherapist, does this exception apply. For all these exceptions, the provider must believe in good faith that disclosure is necessary in these circumstances.<sup>116</sup>

These explicit exceptions for coroners, law enforcement, and funeral directors are puzzling and problematic. Only in very exceptional circumstances does it make sense for these groups of people to have access to a deceased patient’s psychotherapy notes, yet these exceptions present huge risks for disclosing confidential information. The main problem is that coroners, law enforcement, and funeral directors are not

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110. See 45 C.F.R. § 164.508(a)(2)(ii) (2007).

111. 45 C.F.R. § 164.512(g)(1) (2016); 45 C.F.R. § 164.508(a)(2)(ii) (2013).

112. 45 CFR § 164.512(f)(4) (2004).

113. *Id.*

114. Leslie, *supra* note 3.

115. 45 CFR § 164.512(g)(2) (2004).

116. *Does HIPAA Permit a Provider to Disclose PHI About a Patient If the Patient Presents a Serious Danger to Self or Others?*, U.S. DEP’T HEALTH & HUM. SERVICES., <https://www.hhs.gov/hipaa/for-professionals/faq/520/does-hipaa-permit-a-health-care-provider-to-disclose-information-if-the-patient-is-a-danger/index.html> (last reviewed July 26, 2013).



covered by HIPAA and the Privacy Rule.<sup>117</sup> This means that once these groups of people qualify for an exception and access information in the notes, the Privacy Rule does not apply and they could disclose the information to anyone. These risks far outweigh the benefits of the limited exceptions.

## VI. SUMMARY OF CURRENT DISCLOSURE RIGHTS OF PSYCHOTHERAPISTS UNDER THE PRIVACY RULE

The current provisions under the Privacy Rule that discuss disclosure rights of psychotherapists regarding deceased patient's psychotherapy notes are ambiguous and conflicting. Through textual interpretation, regulatory history, and policy rationale, this Note has reached several conclusions. First, unless deceased individuals authorized access to their personal representatives before their death, psychotherapists cannot disclose notes to personal representatives for any reason. Second, unless deceased individuals authorized access to their specific family members or friends before their death, psychotherapists cannot disclose notes to family members or friends for any reason. Finally, psychotherapy notes are disclosable fifty years after the death of the individual.

## VII. RECOMMENDATIONS

Because of privacy concerns regarding psychotherapy notes, personal representatives should not have access rights to a deceased individual's notes. While the current provisions do not permit this type of access, they are written in a way that is confusing and contradictory. To ensure that mental health professionals have a uniform understanding of their responsibility towards personal representatives, HHS needs to amend the personal representative provision (45 C.F.R. § 164.502(g)(4)). HHS needs to explicitly state that psychotherapy notes are not disclosable to personal representatives. In addition to amending the Privacy Rule, HHS should also create guidance explaining that psychotherapy notes are not disclosable to personal representatives on the HHS.gov website. This is important because the HHS website is one of the primary ways that HHS communicates provisions of the Privacy Rule to the general public.<sup>118</sup> There is, however, an exception that should be established for situations in which a personal

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117. See 45 C.F.R. § 160.103 (2013).

118. *HHS Web Governance Charter*, U.S. DEP'T HEALTH & HUM. SERV., <https://www.hhs.gov/web/governance/index.html>. (last visited Aug. 29, 2018).

representative needs access to the notes to pursue a wrongful death claim. This exception is discussed later in this section

Likewise, HHS needs to make it explicit that family members, relatives, or other individuals who were involved in the individual's care or payment for care prior to the individual's death do not have access rights to psychotherapy notes. HHS needs to amend the Privacy Rule to include this type of explicit provision in 45 C.F.R. § 164.510(b)(5). Additionally, HHS should update its website to include guidance about the proposed provision to make it even clearer that family members, relatives, or others do not have access to psychotherapy notes. The same exception regarding access to pursue wrongful death claims should apply for family members as for personal representatives.

The current exceptions enumerated in 45 C.F.R. § 164.508(a)(2)(ii) should be removed. The limited exceptions when coroners, law enforcement, and funeral directors would need access to psychotherapy notes are so uncommon that the disclosure of notes in these situations is not worth the risk that one of these individuals could have the power to legally disclose a deceased patient's confidential information.

HHS should create an exception for situations in which a personal representative or family member needs access to the notes to pursue a wrongful death claim. HHS should include an exception that permits disclosure of a deceased individual's psychotherapy notes by the covered entity when requested by the personal representative or family member to pursue a legal action against the originator of the psychotherapy notes. This exception should be included under 45 C.F.R. § 164.508(a)(2) where the other exceptions are stated.

A potential problem may arise with this exception where personal representatives or family members request the notes by saying it is for purposes of pursuing a wrongful death claim against the mental health professional, but in reality, their intentions are for other reasons. One possible way to prevent the problem is to suggest that states adopt procedures that require the personal representative or family member to file an action with the state court. Rather than filing a complaint, it would be a miscellaneous action through which the individual wanting access to the notes gets an order from a judge compelling production of the notes. This recommendation is to show that the requester of the notes is serious about pursuing a wrongful death claim. It would not be burdensome on the courts because there are few malpractice claims filed annually against mental health professionals, such as psychiatrists.<sup>119</sup>

Finally, this Note recommends that HHS amend the 50-year provision (45 C.F.R. § 164.502(f)) so that psychotherapy notes are

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119. See Anupam B. Jena et al., *Malpractice Risk According to Physician Specialty*, 365 NEW ENG. J. MED. 629, 632 (2011) (reporting that 2.6% of psychiatrists annually faced a medical malpractice claim).

excluded from the provision and are *not* disclosable after any period of time following the individual's death; meaning they are protected forever.

This recommendation is made for a number of reasons. First, the amendment would be consistent with the need to provide strict protections for psychotherapy notes of deceased individuals. Policy reasons discussed in Section III support this recommendation. Second, HHS reasoned that the fifty-year period was enough time because approximately two generations have passed since the death of the individual.<sup>120</sup> This means that by the time the PHI was disclosable, close family and friends, people that truly care about preserving the reputation of the deceased individual would likely also be deceased. The problem with including psychotherapy notes within that provisions is that people who suffer from severe mental illness have been shown to die younger than the general population – an average of twenty years earlier.<sup>121</sup> Consequently, psychotherapy notes, which contain sensitive information, and therefore, information with the most potential to harm the reputation of the deceased individuals, may still be accessible to close family and friends fifty years after the individual's death. Therefore, psychotherapy notes should be forever protected from disclosure after the individual's death.

In addition to changing the Privacy Rule, HHS would need to update the documentation on its website to clarify that psychotherapy notes are forever protected after death of an individual. Putting these recommendations in place will safeguard the privacy rights of deceased individuals as well as eliminate uncertainty around disclosure rights for mental health professionals.

## VIII. CONCLUSION

For mental health professionals throughout the United States, the confusing and ambiguous Privacy Rule provisions create uncertainty about disclosure of psychotherapy notes of deceased patients. Currently, HHS and certain professional organizations, such as the American Counseling Association, publish materials that advise mental health professionals to use their professional judgment to determine

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120. Judi Hofman, *Privacy After Death*, AM. HEALTH INFO. MGMT. ASS'N (April 2013), <http://library.ahima.org/doc?oid=106332#.W42APZNKjMU>.

121. Allen J. Frances, *Having a Severe Mental Illness Means Dying Young*, PSYCHOL. TODAY (Dec. 29, 2014), <https://www.psychologytoday.com/us/blog/dsm5-in-distress/201412/having-severe-mental-illness-means-dying-young>.

whether disclosure is appropriate in certain situations.<sup>122</sup> Textual interpretation, regulatory history, and policy analysis reveal that this advice is in violation of the Privacy Rule. Rather than use professional judgement, mental health professionals should be instructed by HHS and other professional organizations that they are not permitted to disclose psychotherapy notes to personal representatives or family members. By amending the Privacy Rule to have explicit provisions that exclude psychotherapy notes of deceased individuals from disclosure, HHS can solve the uncertainty for mental health professional throughout the country. The recommendations in this Note will help increase privacy protection for psychotherapy notes, as well as, prevent future inconsistencies in disclosures.

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122. *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, *supra* note 2. See also David Kaplan, *Obligations for Protecting the Confidentiality of the Deceased*, COUNSELING TODAY (Oct. 7, 2006), <http://ct.counseling.org/2006/10/ct-online-ethics-update-5/>.