

Intersex Parenting: Ethical and Legal Implications of the Treatment of Intersex Infants and the Ramifications for Their Families

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Abstract: In April 2006, a team of physicians at the Medical University of South Carolina performed female genital normalizing surgery on an intersex infant under the care of the South Carolina Department of Social Services. The now eight-year-old adopted “M.C.” has come to identify as the male sex. The surgical assignment of sex and gender to intersex infants is an immensely complex issue involving changing beliefs in medicine, the tensions between the fields of medical science and feminism, and the legal and ethical implications of sex-assignment surgery on an infant. M.C.’s adopted parents now face the tough decisions of whether or not to file a lawsuit on behalf of their son, and, more broadly, determining the best way to raise a child facing these circumstances.

Introduction

In June of 2006, Pam and Mark Crawford browsed the website of the South Carolina Department of Social Services (SCDSS) from their home in Columbia, South Carolina, hoping to find a child to adopt. The couple discovered the profile of one 18-month-old infant, known hereafter as M.C., and they were immediately charmed. The profile listed M.C. as having “special needs,” but Pam, a practicing psychiatrist, and Mark, a soon-to-be stay-at-home dad, knew that they were prepared to meet any and all of the child’s needs. Born in November 2004 in South Carolina to a single mother soon deemed unfit to raise a child, M.C. fell under the care of the SCDSS almost immediately after birth and seemed like a great fit for the Crawford family. After taking a closer look at the website, the Crawfords learned that the term “special needs” referred to M.C. having ambiguous genitalia (Hastings 2013).

M.C. was born as intersex, a blanket term used to describe someone whose genitalia fall somewhere on the spectrum in between the two supposed norms of male and female. Unlike some prospective parents who may have been deterred by this information, the Crawfords felt that this child was meant for them to find. Pam, who was familiar with intersex conditions because her childhood friend had been diagnosed with one, immediately called the SCDSS and urged them not to perform genital normalizing surgery on the child (Greenfield 2014). Unfortunately, the Medical University of South Carolina (MUSC), with permission from the SCDSS, had already performed sex-assignment surgery to give M.C. more typical female genitalia in April (Federal Complaint 2013). Nevertheless, the Crawfords welcomed M.C. into their family about three months after the surgery in August 2006 with full awareness of the psychological and social hardships M.C. may face while growing up.

Seven years later, M.C. lived a relatively conventional childhood, except for one aspect: his gender identity. M.C.’s parents had been honest with him about his experiences as an infant.

They understood the importance of sharing the information about his surgery and recognized that the assigned female gender given to him by the doctors may not be reflective of his true gender identity. When an eight-year-old M.C. began to ask his parents when he would grow a penis, Pam and Mark Crawford knew that something was amiss. At eight years old, M.C. proudly claimed his gender identity as male. His pediatrician, his school, and even his church respected and recognized him as a boy (Hall 2013). With such supportive parents and such a welcoming community, the only thing preventing M.C. from living a carefree life as a male was the irreversible sex-assignment surgery performed on him before he was two years old.

The surgery performed by Dr. Ian Aaronson of MUSC in 2006 did more than permanently assign M.C.'s sex. M.C. was born with a condition known as ovotesticular disorder, which refers to when an individual has both ovarian and testicular internal tissue, and their external genitalia at birth is ambiguous.¹ Dr. Aaronson performed feminizing-gynecoplasty surgery on M.C. on April 18, 2006, removing his one internal testicle, reducing his ambiguously sized phallus to the size of a typical clitoris, and shaping a vagina out of the tissue that remained. These surgeries are not only irreversible but can also damage sexual function by removing nerve endings in the phallus and cause infertility by leaving no functioning internal gonad (Wilson and Reiner 1999). By surgically forcing the infant M.C. to fit into the sex binary of either male or female, Dr. Aaronson and the SCDSS put his future sexual function and fertility at risk—all for a gender identity he would eventually grow to reject.

As the Crawfords continued to help M.C. understand what happened to him as an infant, they were struck by the injustice of the surgery. On top of growing up in a society that already fosters bodily self-consciousness, Pam Crawford explained that her son must come to terms with the doctors who “told [him] that he was not acceptable or lovable the way he was born” (Hall 2013). Mark Crawford recognized that the biggest challenges for M.C. are yet to come. As he grows into his teenage years, M.C. will have to come to understand “that there is this life of sexual behavior that he’s not able to participate in” (Greenfield 2014). Nevertheless, the Crawfords had faith in their son and prepared for the long road ahead.

Other parties were also interested in M.C.'s outcome, and some encouraged the Crawfords to file a lawsuit on behalf of M.C. Advocates for Informed Choice, a legal organization advocating for better treatment of intersex individuals, reached out to the Crawfords with the intent of representing them. The idea of a lawsuit was certainly one that the Crawfords had considered, but they feared that forcing M.C. into the public spotlight would only add another burden for him to carry. The circumstances surrounding M.C.'s surgery were still fairly unclear. Furthermore, with so many different actors and organizations involved, the Crawfords confronted another difficult question: if they did choose to go through with a lawsuit, who exactly would they sue? And on what grounds? Whether or not they chose to move forward with the lawsuit, Pam and Mark Crawford faced the even more complicated dilemma of how to best raise a child while facing these circumstances.

XXY and Other “Ambiguous” Genitalia: Intersex Explained

An estimated 1 in 2000 births result in an intersex condition, also known as a disorder of sexual development (DSD) (Blackless et. al. 2000). Many different conditions fall under this umbrella category of intersex, and they can be the result of genetic, hormonal, or chromosomal

¹ Since both the clitoris and the penis develop from the same biological precursors, a large clitoris on an infant may be mistaken for a small penis, and vice-versa. Intersex literature therefore often refers to these ambiguous external genitalia as “phalluses”.

effects. Human sexual development in utero is a very complex process, with many individual steps that can result in multiple degrees of variability. At some point the medical field draws a line at each of these stages, with anything beyond the line diagnosed as an intersex condition. This arbitrary categorization of such a wide group of congenital conditions relies heavily upon the scientific premise of the institutionalization of two sexes with perfectly clear biological distinctions, with XX indicating female and XY indicating male. The medical field expects virtually no other human genetic trait to uphold such a clean dichotomy and recognizes that, in most cases, environmental effects can produce a window of accepted variability. Yet, when it comes to biological sex, that window is considerably smaller, leading to the numerous classifications that fall under the category of disorders of sexual development (Callahan 2009).

The overwhelming majority of intersex cases that the general public hears about are individuals who have received genital-normalizing surgery. These surgeries vary greatly depending on the type of diagnosis an infant receives. Some patients may not receive a diagnosis until a few months after birth or even until later in life during puberty. In some cases, surgery may be necessary for the health of the child, such as in preventing urinary incontinence or in the removal of non-functioning internal gonads with malignant risk. In many cases, however, the reason for surgery is merely to remove any visual sexual ambiguities. Upon inspection of an infant's external genitalia and perhaps a subsequent chromosomal or genetic analysis, a physician may conclude that sex-assignment surgery is necessary to produce the "optimum sex of rearing" (Wilson and Reiner 1999). This approach dates back to the 1950s and relies on clinicians' ability to determine which gender the child should be raised as.² Believing that gender expression is entirely dependent on the visible sex of a child, physicians often made this decision based on which surgery would be simplest to perform. This tendency led to a preference for assigning the female sex, since it was often easiest for a physician to surgically reduce a large clitoris and construct a passive vaginal canal (Wilson and Reiner 1999). Though physicians would usually inform the families of intersex infants about these decisions, these families often knew little about intersex conditions and often unknowingly gave their consent to medically unnecessary surgeries.

Only in the past few years have these practices begun to change. More contemporary endocrinology recognizes multiple categories of sex, including chromosomal, genetic, and gonadal sex (Callahan 2009). Physicians and medical ethicists have become more skeptical of the ability of an infant to adopt whichever gender was assigned to them at birth, and new research suggests that sex differentiation is even more complex than originally thought (Aaronson 2001). Though this paradigm shift provides an opportunity for medicine to adapt to more dynamic definitions for sex classification, in reality clinicians may simply interpret this new evidence to confirm their already-held beliefs. For instance, the field of neuroendocrinology determined that two critical periods of hormone exposure—one during gestation and one in the first six months of life—are responsible for significant masculinization of the brain and that

² Psychologist John Money first advocated for this "optimum sex of rearing" approach in the 1950s, and his approach has long been considered the golden rule for intersex infants. Money believed that infants, when given the appropriate surgery and hormonal supplements, could be reared as either male or female, regardless of their sex at birth. Money supported his theory with his supposed success in the treatment of David Reimer, an infant male who received a botched circumcision and was subsequently raised as female. As an adult, Reimer later expressed dissatisfaction with the gender assignment and struggled with gender identity and depression until ultimately committing suicide (Wilson and Reiner 1999).

exposure to testosterone during these times may influence a male gender expression later in life.³ This finding is significant for physicians diagnosing an intersex infant because it means that any amount of testosterone in utero or immediately after birth may result in a male gender expression, regardless of genital-normalizing surgery (Hrabovszky and Hutson 2002). Much of this new research suggests that gender acquisition is a more drawn-out process than the 1950s “optimal gender” approach suggests. Yet, instead of discouraging rashness in decisions about intersex infants’ genders, physicians often use these findings to justify sex-assignment surgery before a child is even taken home from the hospital. These surgeries can have harmful consequences that can last through adulthood. Apart from the possible psychological and emotional distress that a person might endure if assigned the wrong sex at birth, they may also experience sexual anxiety, impotence, loss of clitoral sensitivity, and general lack of sexual function (White 2013).

In collaboration with activist groups like the Intersex Society of North America (ISNA), clinicians are beginning to organize to discourage surgery on intersex infants. After the National Institute of Health declared the clinical management of DSDs a crisis situation in 2006—just around the same time M.C. underwent surgery—a collective of clinicians and intersex activists developed a new standard of care for the treatment and management of DSDs. These new guidelines encourage coordination between specialists across several fields, such as endocrinology, urology, and psychiatry, in order to improve the quality of care for intersex patients. The collective also presented a more cautious approach to genital-normalizing surgery, emphasizing the difference between medically necessary and aesthetic surgeries. Finally, the collective called for a new classification system for intersex disorders (Hughes et al. 2006). Though these policy suggestions received much praise from the intersex community, the implementation of these practices since 2006 has been slow. Nevertheless, several voices within the medical community still emphatically encourage the adoption of those practices outlined in the new standard of care. One of those prominent figures is Dr. Ian Aaronson, founder of the North American Task Force on Intersex, who also happens to be the same physician that performed sex-assignment surgery on M.C. in April 2006 (Intersex Society of North America 2000).

For the Sake of Normal: Science, Gender and Sex

The scientific community has only recently begun to acknowledge the distinction between sex and gender, with sex referring to the biological and gender referring to the social. This recognition marks a huge success for intersex, LGBT, and feminist movements, all of which consider gender to be a social construct to some degree. Feminist biologist Sarah Richardson attributes much of this progress to the higher number of feminist scientists in the 1980s and 1990s. She argues that the gender-critical perspectives associated with the feminist movement revolutionized the way the scientific community speaks and thinks about sex, questioning earlier models about sex differentiation and providing valuable new perspectives, interpretations, and critical discourses. The previous prevailing theory hailed the one SRY gene found on the Y chromosome as the “master gene” that could *activate* male sex development when present, as

³ Neuroendocrinology employs the terms “masculinization” and “feminization” to describe the relative quality of sex differentiation of the brain. These terms do not imply a rigid binary between male and female brains. Instead, they describe a spectrum of sex differentiation, so that a female brain can be masculinized and de-feminized with the addition of excess testosterone, just as a male brain can be feminized and de-masculinized with the removal of testosterone.

opposed to the *passive* female development when SRY was not present. Thus, sex development research almost exclusively focused on the male model, which reinforced a hierarchy of male over female and solidified the dichotomy of two opposing sexes (Marshall Graves 2000). Feminist discourse allowed scientists to describe the errors of these models within a powerful, systematic, critical perspective and resulted in the development of a new genetic theory of sex differentiation, which in turn had profound impacts on the medical treatment of intersex conditions (Richardson 2008).

While the above example is evidence of how feminism can reinvent science, the opposite is also true. This paradoxically agonistic yet mutually beneficial relationship between feminism and science resounds throughout much of the new research on intersex conditions. For instance, neuroendocrinology research suggests that hormonal exposure in the critical window immediately after birth may affect gender expression later in life, tying gender to the biological and complicating the accepted distinction between gender and sex (Hrabovszky and Hutson 2002). And since genital-normalizing surgery on intersex infants upholds traditional beliefs about sex and gender, scientific research on intersex development provides a unique opportunity to challenge and subvert those ideas (Rosario 2009). Intersex politics therefore have the ability to not only blur the lines between the sex binary but also between the gender binary, a major goal of post-modern feminism. But most intersex activists, including the ISNA, would not support that feminist stance.⁴

In fact, the standard of care produced in part by the ISNA in 2006 actively promotes the assignment of a gender to intersex infants at birth. While it does not advocate sex-assignment surgery to support this gender assignment, the ISNA suggests that parents of intersex infants should choose a gender for their children and raise them as such until the child is old enough to either confirm or reject their assigned gender (Intersex Society of North America 2006). This approach is admittedly much more progressive than the traditional medical reliance on surgery, yet it still reaffirms the gender binary—implying that a person is either feminine or masculine, male or female—that the feminist, LGBT, and intersex movements describe as problematic.⁵

The recognition of the possibility of error, however, is significant. Avoiding surgical assignment at birth allows the individual some degree of control over their gender and sexual expression later in life and suggests the fluidity of both gender and sex. Parents of intersex children are then faced with the challenge of explaining this unique situation to their children as they age, as Mark and Pam Crawford do with M.C. Parents like the Crawfords must simultaneously encourage their children to embrace their gender identity while also explaining their inherently subversive role in society. Raising children to be comfortable with their gender expression in a society so opposed to difference is something with which all feminist parents must grapple, but intersex cases like these allow for the examination of the more visible aspects of this struggle.

Legal and Ethical Perspectives of Intersex Treatment

Though the treatment of intersex conditions has sparked much debate in the medical field over the past few decades, shockingly little discussion of intersex politics has appeared in United States courtrooms. In fact, only a handful of cases even indirectly related to intersex treatment

⁴ It is worth noting that the majority of contemporary feminists do not actively advocate for the deconstruction of categories of gender, but that post-modern feminism is distinctly associated with such goals.

⁵ Though the ISNA guidelines do encourage the assignment of gender to an intersex infant, they also make a point to recognize that some intersex people may not fall within the gender binary, just as some non-intersex people do.

exist from around the world. This number is even more surprising considering the many legal issues at stake in intersex cases, especially ones involving genital-normalizing surgery.

Julia Greenberg, an attorney associated with ISNA, considers those legal issues to include marital rights (due to sex determination), threats to reproductive and sexual capabilities associated with surgery, informed consent, sex discrimination, and the right to privacy (Greenberg 2013). The concerns raised in intersex cases bear some resemblance to other forms of LGBT politics, particularly cases involving transgender issues.⁶ Therefore, some relevant transgender legal precedents involving sex-assignment surgery can also be applicable to the intersex cases.

One case in Colombia in 1999 involved a male infant whose penis was mutilated during circumcision. The physicians performed genital-normalizing surgery and instructed the parents to raise the child as a girl. The Colombian court ruled in favor of the child and established that consent for gender assignment must come from the individual receiving surgery, arguing that the genital-normalizing surgery was not a pressing matter and could wait until the child was older. The Colombian court upheld this decision in two later cases involving intersex infants, establishing that the state could intervene to protect an infant against even their own parents' decisions about surgery (White 2013).

Even though they took place outside of the United States, these Colombian examples were the first to identify the right to self-determination in cases involving surgery on infants. If the Crawfords decided to file a lawsuit on behalf of their son, this right to self-determination would likely be central to their legal argument. The legal precedents described above, however, are the only ones of their kind and may not be fully translatable to a case in the United States legal system. Nevertheless, they establish some guidelines for state intervention into the surgical gender assignment of infants.

Additionally, the fact that M.C. was in the care of the state of South Carolina at the time of his surgery adds another level of complexity to his situation. Not only was he unable to consent to surgery at sixteen months old, but he also did not have parents advocating on his behalf. Therefore, the many physicians and social workers were acting as agents of the state when they made the collaborative decision for surgery. That decision by government actors denied M.C. the right to self-determination protected by the Fourteenth Amendment.⁷

However, if M.C.'s parents had been present to make the decision about surgery, they result may have been the same. In fact, it could be argued that the collaboration between many qualified clinicians—one of whom is a leading expert in the field of intersex treatment—ensured that M.C. received the best care possible. Dr. Ian Aaronson, the pediatric urologist who ultimately performed surgery on M.C., was very transparent about the decision-making process, which involved several meetings between SCDSS agents and MUSC physicians. Since M.C.'s surgery occurred at sixteen months of age, the team of clinicians spent a lot of time considering their possible options before electing to perform surgery. They performed numerous diagnostic tests to analyze M.C.'s chromosomal, genetic, and hormonal sex. Dr. Aaronson's published work

⁶ The parallels between intersex advocacy and other LGBT activism continue to grow as intersex becomes a more widely recognized category, with strategies for intersex advocacy—such as the invocation of intersex as a human rights issue—being remarkably similar to those seen in other LGBT activism.

⁷ Legal scholar Ryan White explains that the right to self-determination is a common law concept in the United States that is protected under the constitutional guarantee of liberty in the Fourteenth Amendment. By performing permanent body-altering surgery without M.C.'s consent, the physicians violated the Due Process Clause of the Fourteenth Amendment.

on intersex treatment clearly reflect his caution in assigning a gender to an intersex infant, yet, in his professional opinion, he believed that it was in the best interest to raise M.C. as a female. Dr. Aaronson and his team of clinicians sent their recommendation for feminizing surgery to the SCDSS with the understanding that they could be wrong about M.C.'s future gender identity (Federal Complaint 2013). In fact, Dr. Aaronson's earlier work stated that although a physician's recommendations to parents—or in this case, the SCDSS—about the chosen gender of an infant were “hopefully permanent, [they] must at the onset be regarded as provisional” (Aaronson, 2001). Dr. Aaronson, aware of the possible psychological effects of assigning a child the wrong gender, also understood the consequences of exposures to sex hormones early in life. Though M.C. did later grow to reject the assigned gender, it is clear that Dr. Aaronson and his team made a thoughtful and informed decision at the time with the best interests of M.C. in mind.

Right to Life, Liberty, and Genital Integrity?

Considering the medical, ethical, and legal issues at play, Pam and Mark Crawford had a tough decision ahead of them. Both the Advocates for Informed Choice and the Southern Poverty Law Center, two legal organizations specializing in civil rights issues, believed that the Crawfords had a strong case in both state and federal courts. But if they chose to go forward with a lawsuit, M.C.'s body and gender expression would fall under even more public scrutiny. Raising an eight-year old is hard enough as it is, but Pam and Mark must raise an adopted intersex and effectively transgender eight-year old in a culture that strongly opposes differences. Would they be able to accomplish this while in the middle of a large-scale, likely public lawsuit?

When the Crawfords originally browsed the SCDSS website in June 2006, they were not hoping to become champions of a social justice cause—they were hoping to become parents. If nothing else, M.C.'s case reveals just how complicated parenting decisions can be in a culture with constantly evolving social norms. Pam and Mark Crawford prioritized M.C.'s well-being and recognized the emotional toll a lawsuit may place on him. From that perspective, filing a lawsuit was likely not the best choice of action. After all, what did M.C. personally stand to gain from the lawsuit? Could the U.S. court system legally and emotionally legitimize the gender identity of an eight-year old intersex child, or was that a job solely for his parents?

However, the Crawfords also clearly recognized the significance of M.C.'s position in relation to the greater movement for intersex rights. If filed, M.C.'s case would be the first of its kind in the United States, and it could be a chance to prevent future intersex children from going through the same experiences M.C. had. But what were the risks of making M.C. a poster child for the intersex movement?

And *if* they were to pursue legal action, the questions of *who* and *for what* to sue were equally unclear. Dr. Ian Aaronson—the physician who performed the surgery on M.C. and led the committee that reached that decision—is himself one of the leading scholars on the treatment of intersex infants, so he could hardly be accused of negligence. And the lack of legal precedents on this topic in the United States could make this a landmark case, but it also made it that much more difficult to construct legal arguments to support the Crawfords' cause.

Whether they chose to move forward with a lawsuit or not, it was certainly not an easy path ahead for M.C. and his parents. The Crawfords were proud of the eight-year-old son they raised and wanted justice for him. But more importantly, they wanted to encourage M.C. to live the life he deserves, free of bodily shame. The Crawfords now had to carefully consider the best way to help M.C. come to terms with his experiences as they decided whether or not to file a lawsuit, a question they will continue to be confronted with throughout the rest of M.C.'s life.

Epilogue

On May 14, 2013, Advocates for Informed Choice and the Southern Poverty Law Center filed lawsuits on behalf of the Crawfords in both state and federal courts of South Carolina. The complaints named Dr. Ian Aaronson and his team of physicians, as well as several SCDSS employees, as defendants and argued that the defendants violated the Due Process Clause of the Fourteenth Amendment. In May 2014, a district judge allowed the case to move forward in a preliminary ruling, stating that “M.C. has sufficiently alleged that the defendants violated at least one clearly established constitutional right” (Tamar Mattis 2014).

On January 26, 2015, however, the 4th U.S. Circuit Court of Appeals reversed the district court’s May 2014 ruling and dismissed the federal suit, claiming that the defendants could not be held liable for the Crawfords’ constitutional claims “...because the law in this jurisdiction in 2006 did not provide sufficient notice that they were violating the Constitution” (Southern Poverty Law Center 2015). This ruling did not necessarily deny that M.C.’s constitutional rights had been violated, but rather that Dr. Aaronson and his team of physicians could not be held liable for violating those rights, given their knowledge at the time:

...we find that no then-extant precedent gave fair warning to those involved in the decision regarding M.C.’s surgery that they were violating his clearly established constitutional rights... (Unpublished 4th Circuit Ruling 5).

The Crawfords’ case alleged Fourteenth Amendment substantive and procedural due process violations, specifically that the actions of the defendants “violated his clearly established constitutional right to procreation” (Unpublished 4th Circuit Ruling 7). However, the 4th Circuit Court ruled that the complainant must prove that “the state of the law in 2006 gave the defendants fair warning that their alleged treatment of M.C. was unconstitutional” (Unpublished 4th Circuit Reading 9). In other words, Dr. Aaronson and his team of physicians must have reasonably known that their actions violated M.C.’s constitutional rights at the time of the surgery. M.C.’s complaint cited several previous rulings dealing with reproductive rights, including *Planned Parenthood of Southeastern Pennsylvania v. Casey* (1992), *Avery v. County of Burke* (1981), and *Skinner v. Oklahoma ex rel. Williamson* (1942). Considering these cases, the court concluded “that the defendants violated M.C.’s clearly established “right to procreation.” However, the court determined “that Casey, Skinner, or Avery [did not] put reasonable officials on notice that they were violating M.C.’s constitutional rights” (Unpublished 4th Circuit Reading 12).

Although we acknowledge the broad statements in these cases about reproductive rights, we cannot say that a reasonable official would understand them as clearly establishing an infant’s constitutional right to delay sex assignment surgery (Unpublished 4th Circuit Ruling 10).

M.C.’s case compared genital-normalizing surgery of an infant to forced sterilization of an individual incapable of consent and alleged that his right to due process was violated by the defendants not seeking a hearing before performing the surgery. The court disagreed that such precedent would have been established at the time of the surgery:

We find, however, that reasonable officials in 2006 did not have fair warning that they were violating M.C.’s clearly established rights by not seeking a hearing before performing, or consenting to, the sex assignment surgery.

M.C.'s citations to state statutes and cases are unpersuasive because many post-date 2006, when the surgery took place, and all come from outside South Carolina, where the surgery took place (Unpublished 4th Circuit Ruling 15).

The ruling of this federal court does not preclude a state court ruling in favor of M.C., and his state case against the defendants continues to move forward as of March 2016:

In concluding that these officials did not have fair warning, we do not mean to diminish the severe harm that M.C. claims to have suffered. While M.C. may well have a remedy under state law, we hold that qualified immunity bars his federal constitutional claims because the defendants did not violate M.C.'s clearly established rights (Unpublished 4th Circuit Ruling 16).

Despite the dismissal of their federal case, Pam and Mark Crawford recognized the significance of the lawsuit they filed on behalf of their son and hoped that it helped to bring to light the injustices faced by many intersex people and their families. Clearly motivated out of love for their son and a strong sense of justice, Pam stated that “[they] hope[d] that by speaking out and taking legal action, [they] will help other children born with intersex conditions and their families avoid suffering the pain that [their] son will be forced to deal with for the rest of his life” (Tamar Mattis 2014).

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