

Brain, in press

Book Review by Dean Falk

Forgotten bodies, too?

MALFORMED: FORGOTTEN BRAINS OF THE TEXAS STATE MENTAL HOSPITAL. By Adam Voorhes and Alex Hannaford 2014. Brooklyn: powerHouse Books ISBN: 978-1-57687-708-1 Price

Malformed: Forgotten brains of the Texas State Mental Hospital (2014) is a visually gripping, intellectually engaging, and disturbing book. Stunning photographs and captions by Adam Voorhes and text by Alex Hannaford record an, until now, obscure collection of about a hundred brains that were harvested from patients of the Austin State Hospital (known as the Texas State Lunatic Asylum until 1925) and preserved in jars of formalin. The brains were collected from 1952 to 1983 by pathologist Dr. Coleman de Chenar, and were gifted to the University of Texas at Austin within two years of his death in 1985. Some jars hold multiple brains or pieces of many brains, and a few contain additional organs. The book is lavishly illustrated with photographs of brains in unconventional orientations or floating in jars, sections of brains, and labels that are affixed to jars to indicate the disease or condition associated with their contents including: Alzheimer's disease, hemorrhage, meningitis/encephalitis, various kinds of scleroses, cortical atrophy, lissencephaly, macrencephaly, macrogyria, micrencephaly, edema, Down syndrome, cysts, hydrocephaly, and severe developmental anomaly. Some specimens are so malformed that it is difficult to identify their specific parts (e.g., the unlabeled brain on p. 72).

Suggest reproducing figures from p. 162 and/or p. 72 of book about here

The book has four sections: Discovery, History, The Collection, and The Future. In the first section, the authors discuss their discovery of the rare collection of brains that had been languishing "in the bowels of the Animal Resources Center on the campus of the University of Texas" (p. 15) and how the collection motivated their desire to learn more about the patients and their quality of life as wards of the hospital. Voorhes and Hannaford also wanted to preserve the brains in order to foster interest in their beauty, historical importance, and value for teaching and research. The section provides an overview of how the collection has been poorly curated.

The next section (History) reveals that the asylum accepted its first patients in 1861, and that in the early days individuals were committed for "insanity" hypothetically caused by various conditions such as masturbation, epilepsy, menopause, disappointment in love, domestic troubles, religious

excitement, financial embarrassment, problems from war, and excessive study (p. 70-71). As the authors note, “it may sound amusing, but these people actually lost their liberty for having these ‘conditions’ ” (p. 71). Over time, the hospital became overcrowded with about 3,000 patients, which reduced to around 1,000 in the early 70s, and some people continued to be committed for reasons that would today be considered inappropriate. For example, a 14-year-old autistic boy was admitted in 1963, where he remained a ward of the state for 20 years. Poignantly, the authors observe that “the men and women whose brains now sit in jars...would have experienced the ups and downs of life at Austin State Hospital – specifically the turmoil it went through in the 1960s and ‘70s: the overcrowding; the experiments with different forms of treatment (from fresh air and gardening to Thorazine and electric shock therapy)...a life effectively shut off from the outside world” (p. 111). Some of the practices these patients may have experienced were simply horrible:

Following a surprise visit by state mental health officials in June 1970, state Rep. Don Cavness accused some officials at the hospital of mistreating and sexually abusing patients. The reported mistreatment included allowing teen patients to drink alcohol, then stripping them and encouraging them to fight. Those who refused were drenched with waste from bedpans “to make them mad”....He said he’d also received reports about a “quiet room” in which patients were forced to stay alone for up to three days without covers or mattresses. “Their clothes are removed, and other patients are allowed to view them through a screened section.” Former hospital employee and whistleblower Richard Laminack later described the action as “the most ugly, dehumanizing thing you could do to a kid.” (p. 77)

Voorhes was especially moved by one jar from 1983 that contained three Down syndrome (DS) brains and struggled “to understand why a person with this disorder would spend his or her day in a mental institution, particularly in such recent years.” He also “wanted to know their stories” (p. 18). His struggle was reinforced “after learning about the hospital’s history” (p. 105). Like most jars, the one containing the DS brains was affixed with a label that contained three pieces of information: a reference number, condition of the patient(s), and date of death (DOD). (Unfortunately, like the brains, the labels are in various states of decay, so absolutely nothing is known about some of the specimens.) Voorhes thought that the numbers on the jar labels referenced medical records and, as he describes on the front flap of the book, “those records became my secondary obsession.” In 2012, Hannaford made an open-records request to the Texas Department of State Health Services (DSHS) for de-identified medical records associated with labels of 24 specimens in the University of Texas brain collection. However, the

DSHS was unable to locate the requested information partly because “the numbers you cited are not patient record numbers...we don’t know what those numbers are or how to use them to connect a specimen to a patient” (p. 163).

Photo of DS brains in jar from p. 19 of book about here

Since the reference numbers on the jars are not those for patients’ medical records, I was curious about what information might be coded in them. In order to explore this, I organized the specimen numbers that were photographed or mentioned in the book chronologically, from the earliest to the most recent date of death (Table 1). Once the data were so organized, it became apparent that the first part of the reference numbers code the numerical position of the deaths among the 3,759 that were recorded (i.e., numbered) at the mental hospital from the latter part of 1952 through early 1983. For example, the third entry in the table (498-57-1958) is the reference number for the 498th death that was numbered since the collection began in 1952, which was for an individual who died on May 1, 1958. The second part of the numbers, on the other hand, appear to indicate the numerical position of the death among those that were recorded during the year in which the death occurred. According to this interpretation, the 498th recorded death was the 57th that occurred and was recorded in 1958, and the next reference number in the table (526-85-1958) was the 526th brain recorded across the years until the DOD and the 85th that occurred and was reported in 1958.

Table 1 about here

In keeping with this interpretation, the first and second parts of the reference numbers increase by equal increments within years (e.g., see the entries for 1973). It is clear from Table 1 that Dr. de Chenar, whose collection eventually accumulated around 200 brains (p. 111), selectively collected only some of the brains from patients who died. The brains were harvested during autopsies, but it is unclear how many of the deceased patients whose brains were not collected were autopsied. However, whether or not the brain of the first patient whose death was recorded each year was collected, the number assigned to that person’s death would have had 01 as its second part; the number of the brain of the second person to die that year would have had 02 in second place, and so on until the end of the year. Significantly, and, again, assuming that my interpretation is correct, these data allow one to calculate the number of deaths recorded (i.e., numbered) during specific years or, when data are incomplete, during spans of more than one year (Table 1). As an example of how the annual recorded deaths in Table 1 were calculated, the number of recorded deaths in 1958 was determined to be 170 by

subtracting the 441 deaths that were recorded by 12/31/57 (determined by subtracting the second part of any reference number ending in 1958 from its first part [498-57 = 441]) from the 611 deaths that accumulated by the end of 1958 (determined similarly from reference numbers that end in 1959 [633-22 = 611]), thus $611-441=170$. Table 1 is internally consistent -- the data reported/calculated in the second column (i.e., 441 deaths recorded from 1952-1957, the annual deaths calculated and summed from 1958-1982, and the 4 deaths recorded for the first part of 1983) add up to the first part of the most recent (2/10/1983) reference number, namely 3,759.

Assuming my interpretation is correct, it can be seen from Table 1 that the greatest number of recorded annual deaths at the Texas State Mental Hospital occurred during the 1960s, with 2,308 for the decade and a peak average of ~ 256 /year in 1962-1963. Unfortunately, little information is provided about the number of patients who lived at the hospital when these deaths occurred: When it opened in 1861, the asylum housed 160 patients (p. 68); by the early 70s the number of patients was down to about 1,000 from 3,000 (p. 77). In 1974, the number was down to about 800 (p. 77). According to the authors, after the scandalous revelations noted above, a major reorganization took place in the early 1970s and the treatment of patients began to improve. Table 1 is consistent with this observation: in 1969, just prior to the mid-1970 exposure of practices such as placing naked patients in the "quiet room" or dumping human bedpan waste on them to make them fight, 216 deaths were recorded from a patient population that was declining toward about 1,000 individuals; during the next three years (1970-1972), the annual number of recorded deaths dropped from 216 to an average of about 70, although population size was still above the 800 it would reach in 1974.

Table 1 about here

The third section of the book (The Collection) describes how the brain of mass murderer Charles Whitman came to be part of the collection, although he had not been a patient at the mental hospital. Whitman died while carrying out the so-called Texas sniper shootings on August 1, 1966. Dr. de Chenar subsequently performed an autopsy on his body and harvested the brain. This specimen became part of de Chenar's collection, which was transferred from the Texas State Mental Hospital to the University of Texas at Austin around 1987. During their (unsuccessful) attempt to locate Whitman's brain, Voorhes and Hannaford discovered that approximately half of the 200 brains in the collection had gone missing after its transfer. This section of the book describes the authors' frustrated efforts to locate the missing brains, and the finger-pointing that went on between officials when asked to explain what happened to them: "And yet today, nobody, apparently knows where half of this valuable collection has gone. Were they given back to the hospital? Were they sold? Were they given away? Will we ever find out?" (p.

124). After *MALFORMED* was published, news reports quoted University of Texas officials as stating that the missing brains were destroyed in 2002, and that they are looking into it. (The officials also said that no evidence links the specimens to Whitman's missing brain.)

The final section (The Future) makes the case that MRI technology and new molecular techniques that facilitate recovery of usable DNA from fixed brains that were embedded in celloidin as far back as the early 1900s increase the potential research value of the collection. The authors reiterate that locating the relevant medical (and, presumably, autopsy) records would further enhance the brains' value for both teaching and research. In light of their desire to see the collection used for more research in the future, it is surprising that the book lacks an index. (Table 1 below provides page numbers for the brains that are shown in photographs or discussed in the book.) The variety of anomalies represented in the collection also enhances its potential importance for researchers. For example, I and my colleagues who are currently engaged in collaborative paleoanthropological research that focuses on Down syndrome have had difficulty locating whole DS brains. Thanks to this book, we now know where there are three of them.

In addition to being an enthralling read with exquisite photographs, *MALFORMED* is written with great sensitivity and respect for the patients whose brains became part of the collection. The book raises unnerving questions about what went on at the mental hospital when the donors of those brains were still alive. In my opinion, these questions become even more disturbing in light of the large number of deaths that seem to have occurred at the hospital, especially during the 1960s (Table 1). Perhaps while officials at the University of Texas are looking into the 2002 destruction of about half of the collection of brains, other authorities should examine the deaths of the patients at the Texas State Mental Hospital who made the collection possible.

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Table 1. Number of annual deaths recorded for patients at the Texas State Mental Hospital from 1952-1983. Specimens are organized from the earliest to most recent date of death (first column). Recorded deaths were calculated by the reviewer from brain reference numbers published in *MALFORMED* (reproduced in the second column). The conditions indicated on jar labels are mostly in archaic Latin, reproduced verbatim in the third column; and each specimen is indexed to pages in the book in the fourth column.

Date of death (DOD); recorded deaths per year(s)	Brain reference # (overall cumulative deaths – cumulative deaths in year-to-date – year of death)	Condition on label (as stated)	Page references (in <i>MALFORMED</i>)	Comments
10/4/1952	?-9-1952		42	? = illegible #, "E981" on label
cumulative numbered deaths by 12/31/1957	441			calculated by reviewer
5/1/1958	498-57-1958	makrencephalia	36, 92	
6/25/1958	526-85-1958	meningoencephalitis	74-75, 97-99	
recorded deaths 1958	170			calculated by reviewer
2/5/1959	633-22-1959	haemorrhagia subarachonidealis frontotemporalis	86-87	
10/16/1959	752-141-1959	mikrenkephalia	142-143	
recorded deaths 1959	184			calculated by reviewer
2/10/1960	828-33-1960	hydrocephalus internus	20-21, 106-107	
5/27/1961	114-86-1961	atrophia diffusa corticis convexitatis cerebri	58-59	typo: 114 should probably be 1114
recorded deaths 1960-1961	477 (~ 239/yr)			calculated by reviewer (independent of previous entry, but consistent with its corrected typo)

8/30/1962	1474-202-1962	cyst postemoll. hemisphaerii lat. dextri	10, 96	
recorded deaths 1962-1963	511 (~ 256/yr)			calculated by reviewer
7/23/1964	1892-109-1964	cysta subarachnoidalis multiplex cerebri	90-91	
8/1/1966			121	no photograph, donor, Charles Whitman was not ward of hospital; autopsy report = case no 621966
8/6/1966			121	no photograph
recorded deaths 1964-1968	1104 (~ 221/yr)			calculated by reviewer
2/17/1969	2921-34-1969	M. Alzheimeri	127-129	
2/19/1969	2924-39-1969	atrophia lob...?	50-51, 156-157	probable typo: 2924 should be 2926; ? = can't read entire condition
2/26/1969	2934-47-1969	oedema cerebri uraemia	29	
5/7/1969	2976-89-1969	cavum postemolliticum diencephali l. d. ggll. extrap., thalamique	124-125	
recorded deaths 1969	216			calculated by reviewer
4/30/1970	3139-36-1970	haemorrhagia subarachnoidalis	43, 103	
5/6/1970	3143-40-1970	hydrocephalus internus	176	
12/28/1970	3187-84-1970	agyria lobi. fron. Lat. utr.	38-39, 93	
6/5/1971	SE-A-1971	haemorrhagia subarachnoidealis	54-55	Ref. no. suggests donor was not a ward of the hospital
recorded deaths 1970-1972	211 (~ 70/yr)			calculated by reviewer; by early 70s, number patients down to ~ 1000 patients 3000 (p. 77)
8/22/1973	3354-40-1973	hydrocephalus internus atrophis cerebelli	168-169	
8/24/1973	3356-42-1973	sclerosis tuberosa	25, 136-137	
10/27/1973	3366-52-1973	mikrenkephalia	162	
12/5/1973	3372-58-1973	mikrenkephalia	11, 150-151	

recorded deaths 1973-1974	119 (~ 60/yr)			calculated by reviewer; ~ 800 patients in 1974 (p. 77)
1/?/1975	3436-0?-1975	hydrocephalus internus	20	? Illegible #s
2/27/1975	3440-07-1975	hydrocephalus internus et externus	137-139	
8/18/1975	3466-33-1975	micrencephalia	112-115	
recorded deaths 1975	56			calculated by reviewer
1976	3495-6-1976		147	DOD presumed from ref. number
1976	3497-8-1976		173	DOD presumed from ref. number; label: "please keep" "Res"
6/6/1976	3507-18-1976	makrencephalia	6, 80-81	
recorded deaths 1976-1977	87 (~ 44/yr)			calculated by reviewer
1/6/1978	????-02-78	severe developmental anomaly of the brain	131-135	? = illegible #s
1978	3608-32-78		26-27	DOD presumed from ref. number
6/17/1978	3627-51-78		68-69	label: "case 83970"
recorded deaths 1978	58			calculated by reviewer
1979	3662-28-79	dysplasia cerebri	121	no photograph
recorded deaths 1979	46			calculated by reviewer
1980	3693-13-1980	sclerosis rhombocephali macrogyria microgyria dysplasia hemisphaeriorum	46-47	DOD presumed from ref. number
recorded deaths 1980-1982	75 (25/yr)			calculated by reviewer
2/10/1983	3759-04-83	Down's syndrome	18-19, 30-31, 48-49, 94-95,104	jar contains three DS brains

Legend for image from p. 162: In addition to the three pieces of information discussed in the text, most jars had red dots or red and green dots affixed to them, but without medical records the authors could not determine their meaning. (The reviewer suspects the dots might be related to periodic topping off of fluid in the jars.)

Legend for image from p. 72: Use the one from p. 73 of the book

Legend for photo from p. 19: The first jar that moved Voorhes was this one, which contains three Down syndrome brains.