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The Legacy and Contemporary Relevance of Nephrologists

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The Legacy and Contemporary Relevance of

3HUFLYDOIV ZRQGHM@ Ethics WUHDWLVI

RI \HOORZ IHYHU +H FUHDWHG D VFLHQWL¿F \ subjects was intentionally exposed to the bite of the mosquito, which, as ZH DOO NQRZ WRGD\ ZDV WKH YHFWRU RI WKH D WUHPHQGRXV VFLHQWL¿F VXFFHVV DQG 5H WKH QDPLQJ RI D SURPLQHGW \$UP\ KRVSLWDC IRU DOOHJHGO\ KDYLQJ GHYLVHG WKH ¿UVV is that some of these accounts of Reed are more the stuff of legend than KLVWRULFDO IDFW 0RUHRYHU 5HHG¶V H[SHU some serious moral issues.

)LUVW WKH VR FDOOHG FRQVHQW IRUP ZDV FODLPHG LW ZDV SULQFLSDOO\ DQ HPSOR\F experimental design in the study had been in part anticipated and used by DQ ,WDOLDQ H[SHULPHQWDO LQYHVWLJDWRU K\SRWKHVLV KDG DOUHDG\ EHHQ GHYHORSHG D &XEDQ SK\VLFLDQ 7KH H[SHULPHQW LQ %U criticized as unethical in the treatment of human subjects by the great &DQDGLDQ 7KH] \$À à
DisEti • P 70 EQ à0 V V P€`0 [H] 05iH]RQO01

5HHG LV D FDVH RI ORRPLQJ PRUDO SUREOH
made all the more interesting because Reed is generally presented, still
WRGD\ DV DQ \$PHULFDQ KHUR %XW , ¶YH VDL
PRUDO LQVHQVLWLWYLVW\ LQ PHGLFDO UHVHDUF
this paper, and I need to return at this point to the research in Germany and
WR WKH ¿QGLQJV DW 1XUHPEHUJ

Nazi Physicians, the Nuremberg Trials, and the Nuremberg Code

Nuremberg is the most important watershed event in the more than
\HDUV RI UHVHDUFK LQYROYLQJ KXPdq V
cruelties in Germany were often administered by well trained and
prominent physicians. Their extraordinary evil was to change how we
YLHZ WKH XVH RI KXPdq VXEMHFWV LQ VFLH
FKDQJH LV IRUHYHU %XW RQH RI WKH FRQFO
is that we have not resolved all of the problems that became so obvious in
Nazi Germany.

7KH 1XUHPEHUJ 7ULDOV DQG WKH 1XUHPEH
major curbs on research in any nation. The succinct Nuremberg Code
ZDV SUHVFULEHG LQ DV ~~United States~~ WKH MX
Brandt WKH 1XUHPEHUJ WULDO RI 1D]L SK\VL
HQJDJHG LQ VR FDOOHG ELRPHGLFDO H[SHUL
it is a common misconception that these were the earliest examples of
willfully harmful, vicious research on unwilling human subjects, the
Nazi experiments were indeed unprecedented in the extensiveness and
H[WUHPLW\ RI WKH KDUP DQG VXIIHULQJ WR ZH
many victims. Using subjects drawn from the populations of concentration
FDPSV -HZV]\SVLHV 3ROHV DQG 5XVVLDDQV
effects of ingesting poisons, intravenous injections of gasoline, immersion
LQ LFH ZDWHU DQG WKH OLNH ,QHFWLRQ Z
IHYHU YLUXV DV ZHOOD DV NLOOLQJ SHRSOH V
were common parts of an extensive pattern of “medical” experiments.

Nazi euthanasia (a dreadful euphemism for the original meaning of the
WHUP ³HXWKDQDVLDD´ SURJUDPV LQYROYLQJ S
SHRSOH 7KHVH SURJUDPV ZHUH H[SOLF
had “worthless lives” and were social “undesirables.” Often doctors made a
decision whether someone was a social undesirable, and therefore whether

HXWKDQDVLD ZDV DSSURSULDWH %HLQJ VLFM

and other atrocities committed in the name of medical science. . . .

,Q PDQ\ F DVHV H[SHULPHQWV ZHUH SHUIRU
ZHUH FRQGXFWHG DW UDQGRP IRU QR DGI
XQGHU UHYROWLQJ SK\VLFDQ FRQGLWLRQV
conducted with unnecessary suffering and injury and but very little, if
DQ\ SUHFDXWLRQV ZHUH WDNHQ WR SURWH
from the possibilities of injury, disability or death. In every one of
the experiments the subjects experienced extreme pain or torture,
and in most of them they suffered permanent injury, mutilation, or
GHDWK HLWKHU DV D GLUHFU UHVXOW RI V
adequate follow up care.

'U \$QGUHZ ,Y\ ZKR VHUYHG GXULQJ WKH
RQ VFLHQWL¿F DQG HWKLFDO TXHVWLRQV FU
GRQH IRU LWV SRRU VFLHQWL¿F GHVLJQ LU
DUJXHG WKDW WKH PHGLFDO WUDJHGLHV ZHU
experiments, which revealed nothing of use to “civilized medicine.”

7KH H[WUHPH GLVUHJDUG RI HWKLFV LQ WKH
VXEMHFWV LV DOO WKH PRUH UHPDUNDEOH LQ
had enacted, on moral grounds, strict regulations or guidelines (Richtlinien)
to control both human experimentation and the use of innovative therapies
LQ PHGLFLQH ,V VXHG E\ WKH 5HLFK¶V +HDOV
remained binding law throughout the period of the Third Reich, but there
is no evidence of any serious attempt to understand or enforce this law,
HLWKHU LQ PHGLFLQH RU JRYHUQPHQW DIWH
,W ZDV GHPDQGHG XQGHU WKLV ODZ WKDW FR
as appropriate) must always be given “in a clear and undebatable manner.”
4XHVWLRQV RI WKH QDWXUH RI DSSURSULDW
careful research design, and special protections for vulnerable subjects
were all delineated in these guidelines. Human experimentation was
declared impermissible without consent, and absolutely impermissible
with dying patients.

,W LV D VSHFLDO LURQ\²D SKHQRPHQDO KL
nation appears to have had such morally and legally advanced regulations
DW WKH WLPH RI WKH 1DJL DEXVHV \$ VHFR
1XUHPEHUJ &RGH LV ZLGHQ\ DVVXPHG WR EH
KLVWRU\ RI UHVHDUFK HWKLFV WR GHDO ZLW

UHJXODWLRQV DFWXDOO\ FRQWDLQ QR OH
the Code itself.

an investigator may conduct research and delineates the conditions under which a subject has the ability to volunteer and, in all cases, to withdraw from the research even after it has begun.

:KHWKHU WKH 1XUHPEHUJ &RGH ZDV LQÀXH
is historically controversial, but, somewhat embarrassingly, it does not appear to have had much of an effect in the United States, even though our MXGJHV KDG GHOLYHUHG WKH MXGJPHQW LQ
the Code. There is one apparent, but not profoundly important, exception WR WKLW SRLQW DERXW LQÀXH QFH 7KH 8 6
Nuremberg Code, but it was a distant and veiled adoption: Having accepted the Code, the Dept. of Defense never seriously attempted to implement the Code in its conduct. This might seem ludicrous and hypocritical, but when ZH FRPH EHORZ WR WKH 'HFODUDWLRQ RI +HO
most countries and institutions have behaved roughly as the Department of 'HIHQVH GLG \$GRSW D FRGH DQG WKHQ GR OL

In any event, to bring this discussion of Nuremberg to a conclusion, WKH 1XUHPEHUJ &RGH VHUYHG

to abuses of the sort we had seen in Germany. Partially in response to
WKLV SHUFHLYHG WKUHDW WKH :RUOG 0HGL
WKH HDUO\ V DIWHU VRPH SULRU GLVFXV
VXLWDEOH FRGH WR GLVWLQJXLVK HWKLFDO I
RI WKH :0\$¶V FRGH ZDV SURGXFHG LQ EXV
XQWLO D PHHWLQJ DW +HOVLQNL LQ /HW P
WKDW WKH 'HFODUDWLRQ RI +HOVLQNL ZDV HC
RI ZHVWHUQ DOOLHV VHHNLQJ WR GR WKH ULJ

a relatively new and untested code of the International Conference on
+DUPRQLJDWLRQ RULJ

7KH)'\$ KDV GHWHUPLQHG DV , GR WKDW
and incomplete document. I have no time to go into the details, but the
PHVVDJHV DUH WZR)LUVW HYHQ LQ D
the Second World War, little had been done to develop research ethics in a
GHWDLOHG IRUP LQ DQ\ FRXQWU\ 1XUHPEHUJ
:RUOG 0HGLFDO \$VVRFLDWLRQ KDG RQO\ D VN
OLWWOH KDG EHHQ GRQH LQ WKH 8QLWHG 6W
*HUPDQ DEXVHV EXW WKHQ IDLOHG WR WDNH

PQD@³

\$Q ,QÁXHQWLDO 6FKRODU +HQU\ %HHFKHU
,PPHGLDWHO\ DIWHU WKHVH HYHQWV XQ D

faced with a seriously wrong situation.

It turns out that he was right and that the abuses reached up to the

medical attention made them readily available subjects. The subjects were also misinformed that research procedures such as painful spinal taps were

D ³VSHFLDO IUHH WUHDWPHQW ´ D SDWHQWOL

care necessary to treat them (that is, to treat whatever could be treated
RI WKH GLVDELOLWLHV WKDW UHVXOWHG IUR
end the study, but without offering any form treatment for the survivors.
7XVNHJHH KDG EHFRPH D WUXH \$PHULFDQ WU
something from this tragedy and almost immediately began to reform the

setting. Sometimes there are excusing conditions for wrong actions

EHFDXVH DOWHUQDWLYH YLHZV DUH XQDYDLO
FRQWH[W EXW DOWHUQDWLYH YLHZV ZHUH D
ZHUH FRQVLGHUHG PDWWHUV RI WKH XWPRV
WR WKH UHOHYDQW SDUWLHV ,W ZDV NQRZQ
WKDW D GHEDWH KDG RFFXUUHG GXULQJ WKH
LQ 1D]L *HUPDQ\ WKDW WKH \$PHULFDQ OH
&RXQFLO KDG VLGHG LQ ZLWK ZKDW ZRXO
WKDW YROXQWDU\ FRQVHQW WR SDUWLFLSDV

the Hippocratic tradition required physicians to put the care of patients

¿UVW QRW WR GHYLDWH UDGLFDOO\ IURP D
KDUP WR SDWLHQWV WKURXJK QRQWKHUDSHX
was a long tradition of post-Hippocratic writings in medical ethics of
¿JXUHV ZKR UHFRJQLJHG QRQWKHUDSHXWLF I
subjects had consented. Thus, requirements such as voluntary consent to
experimentation and protection against harmful interventions had long
been present in the medical community and even were present in some
JRYHUQPHQW SROLFLHV WUDFHDEOH WR WKH

In light of this history, neither physicians nor government and

XQLYHUVLW\ RI¿FLDOV ZKR SDUWLFLSDWHG L
V LQ WKH 8 6 FRXOG SODXVLEO\ DSSHDO V
EHFDXVH WKH\ DQG WKH RI¿FLDOV DW WKHLU
KLJKHU RI¿FLDOV LQ PHGLFLQH FRXOG KDY

contextual moral ignorance. There was ample opportunity for remediation
of inadequate moral beliefs and therefore culpability for the continuance of
those beliefs. The excuse of nonculpable ignorance, then, is not credible.

The Work of the National Commission for the Protection of

+XPDQ 6XEMHFWV

,W LV VWULNLQJ WKDW D FRPPLWWHH WKDV
7XVNHJHH DG KRF DGYLVRU\ SDQHO FRXOG KD
²DQG WKDW ZH ZRXOG QRW OHDUQ PXF
DEXVHV XQWLO <HW DV WKH ¿QDO WRXF
DGYLVRU\ SDQHO¶V UHSRUW DQG ZKLOH QDW
6XSUHPH &RXUW¶V LPSHQGLQJ GHFLVLRQ RQ

Roe v. Wade, newspapers began to publish reports that PHS-supported

research activities of the biomedical and behavioral sciences be brought under the critical eye of, and possibly the control of, impartial persons ZKR ZHUH QRW WKHPVHOYHV VFLHQWLWVWV \$ one that placed responsibility for the protection of human subjects on the shoulders of individual investigators. That is, federal policies relied on the discretion and good judgment of investigators to determine under

assigned to those engaged in the review of research. Several other reports,
ERWK EHIRUH DQG DIWHU UHDFKHG VLPLODU
ZDV DSSDUHQW WR HYHU\ NQRZOHGJHDEOH RE
review in the U. S. is seriously strained and seriously underfunded in many
RI RXU JUHDW PHGLFDO UHVHDFK LQVWLWXW
on notice, and some have even had their federal funding withdrawn.

I have no time to go into what these problems are in particular, but
, FDQ VD\ WKDW WKH\ RFFXU DW PXOWLSOH C
institutions of research medicine. The United States is not in jeopardy of
EHLQJ *HUPDQ\ LQ WKH V DQG LW LV QRW
RI %XW RQH RI WKH PRVW LPSRUWDQW C
Holocaust and from the entire history of biomedical research with human
VXEMHFWV LV WKDW RXU V\ VWHP KDV QHYHU

,QVWLWXWH RI 0HGLFLQH 5HVSRQVLEOH 5HVHDFK
5HVHDFK 3DUWLFLSDQWV (G 'DQLHO ') +DQQD (DG
7KH 1DWLRQDO \$FDGHPLHV 3UHVV

+ \PDQ Y -HZLVK &KURQLF 'LVHVDVH +RVSLWDO 1 <

,Y\ \$QGUHZ 7KH KLVWRU\ DQG HWKLFV RI WKH XVH RI
6FLHQFH -XO\

-RQHV -DPHV + %DG %ORRG QG HG 1HZ <RUN 0D[Z

.DW] -D\ HG ([SHULPHQDWLRQ ZLWK +XPDQ %HL
)RXQGDLRQ

/HGHHU 6XVDQ (DQG 0RUHQR -RQDWKDQ ' 5H
UHVHDFK HWKLFV .HQHG\ ,QVWLWXWH RI (WKLFV -

/HYLQH 5REHUW - (WKLFV DQG 5HJXODWLRQ RI &OLQ
6FKZDU]HQEHUJ QG HG 1HZ +DYHQ <DOH

0DFNOLQ 5XWK 8QLYHUVLW\ RI WKH 1XUHPEHUJ &
1XUHPEHUJ &RGH (G *HRUJH - \$QQDV DQG 0LFKDH
8QLYHUVLW\ 3UHVV SS

0DUVKDOO (UQHVW 'RHV WKH PRUDO SKLORVRSK\ RI
,5% \$ 5HYLHZ RI +XPDQ 6XEMHFWV 5HVHDFK

0LWVFKHUOLFK \$OH[DQGHU 'RFWRUV RI ,QIDP\ 7KH
([WHQGHG HGLWLRQ 7UDQV +HLQ] 1RUGHQ 1HZ <RUN

0RUHQR -RQDWKDQ ' *RRGE\H WR DOO WKDW WKH H
VXEMHFWV UHVHDFK +DVWLQJV &HQWHU 5HSRUW

BBBBB \$SSHQGLFHV , DQG ,, WR 7KH %HOPRQW 5HSRU
RI +XPdq 6XEMHFWV RI 5HVHDFK YROV :DVKLQJWF
DQG 26

2VOHU 6LU :LOOLDP 7KH (YROXWLRQ RI 0RGHUQ 0HGL
DW <DOH 8QLYHUVLW\ RQ WKH 6LOOLDPQ)RXQGDWL
8QLYHUVLW\ 3UHV

3HUFLYDO 7KRPDV 0HGLFDO (WKLFV RU D &RGH RI ,
3URIHVVLQRQD &RQGXFV RI 3K\VLFLDQV DQG 6XUJHR
DYDLODEOH HGLWLRQ LV 3HUFLYDO 1V 0HGLFDO (WKL
1 < 5REHUW (.ULHJHU 3XEOLVKLQJ &RPSDQ\

5RWKPDQ 'DYLQ :HUH 7XVNHJHH :LOORZEURN µ6W
5HSRUW \$SULO

6DVV +DQV 0DUWLQ 5HLFKVUXQG VFkuhleHQ 3U
FRQFHUQLQJ QHZ WKHUDS\ DQG KXPdq H[SHULPHQV
3KLORVRSK\

6PLGRYLFK 9LNHQWL\ >SVHXGRQ\p 9 9HUHVdHII@ 7K
6LPHRQ /LQGHQ /RQGRQ *UDQW 5LFKDUGV

Toulmin, Stephen. The National Commission on human experimentation: procedures
DQG RXWFRPHV ,Q (QJHOKDUGW +7 -U &DSODQ \$
Studies in the Resolution and Closure of Disputes in Science and Technology. New
<RUN &DPEULGJH 8QLYHUVLW\ 3UHV

8QLWHG 6WDWHV Y .DUO %UDQGW 7ULDOV RI :DU &U
7ULEXQDOV XQGHU &RQWURO &RXQFLO /DZ 1R 0LC
8 6 *RYHUQPHQW 3ULQWLQJ 2I¿FH 9ROV DQG

9HDWFK 5REHUW 0)URP 1XUHPEHUJ WKURXJK WKH
9DQGHUSRRO +< 7KH (WKLFV RI 5HVHDFK ,QYROYLQ
&HQWXU\)UHGHULFN 0' 8QLYHUVLW\ 3XEOLVKLQJ *U

:RUOG +HDOWK 2UJDQL]DWLRQ WK :RUOG 0HGLFDO
'HFODUDWLRQ RI +HOVLQNL UHFRPPHQGDWLRQV JXL
UHVHDFK LQYROYLQJ KXPdq VXEMHFWV 1HZ (QJOD

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