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The Journal of Healthcare, Science and the Humanities

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When I was in the 7th grade, now so very long ago, science became part of our grade school curriculum for the very first time. I remember those classes. The first was in astronomy. I believe I did fairly well. My brain was certainly stretched. However, there was a deep, almost personal interest that I remember. It was not an interest in the mathematics of it all. It was not in the formulae or the theories of planetary orbits. Rather I remember my imagination being caught up in the utter beauty and immense power of spinning galaxies, orbiting planets, the alluring idea of a black hole in space, and the overwhelming images of an old star bursting anew in the process of becoming *Nova*.

As I grew older, my fascination with spinning galaxies and with *Novae* continued to come back to me. I was particularly intrigued at one point in my student life by Vincent Van Gogh's 1889 painting, "Starry Night." Here was a man suffering from internal collapse who managed to reach out from his nothingness and painted a portrait of hope and healing in the pulsing and spinning lights of impressionistic images of the moon and stars above a seemingly sleeping village. From those years and even until today, the external fascination of my youth meets the internal energies of Van Gogh's pilgrimage within his self. They are related. They are both *Novae*. Different…but curiously similar. They both have something to do with newness and change, both within and without. However, before proceeding further, it would be helpful to be refreshed on what more precisely is meant by a *Nova*.

Our Journal colleague, Dr. Bruce Boynton, has immensely powerful insights on the nature of what constitutes a *Nova* or, as it is also called, a *Supernova*. Permit me to quote him from a recent discussion.

> The term *Nova* was applied by the ancients to what they perceived as the birth of a new star. In fact, it was the death throes of an old and massive star that had collapsed and exploded with unthinkable power.
>
> But actually we are made of that exact stuff.
>
> A few light elements (hydrogen, helium, lithium and beryllium) were made shortly after the Big Bang; a few more (carbon, nitrogen, oxygen) are forged by nuclear fusion in the core of stars like our sun. But the heavier elements can only be created from the explosions of *Supernovae*. The death of those stars created the very stuff we humans are made of.
>
> Their end enabled our beginning. We are, quite literally, star men and women.

Introduction

A definition…more appropriately a portrait of an exploding experience…an experience that is at the root of what it means to be human…Becoming *Nova*.

As a young boy moving quickly into adolescence, perhaps there was something beautifully primal that made the images of the bursting star being reborn, the *Nova*, so incredibly attractive. However, the attraction of the *Nova* is far more fundamental.

From the time that we are born and emerge from the symbiosis of the womb, each human being subconsciously becomes caught up in a process to find that "other" that alone can complement the new experience of our individuality…and even more deeply can fill the new, singular experience of emptiness within.

At the very basis of who we are and what we do, from the moment the cord is cut we become caught up in the immense energies of Desire. Desire is what leads us to explore, to reach out, to seek that which is different. It is Desire that leads us into all types of places and experiences where we grow and change. In fact, as we come to know ourselves in life, we always seek to become something different. We hunger, thirst, and seek the experience of transformation. We vividly search to immerse ourselves in the untamed fires of self-transcendence. We passionately look to become something "more." We ourselves want to be the star bursting into unbridled newness. We ourselves want to become the *Nova*.

Transformation is a perennial and non-negotiable part of the journey we have as human persons. It is foundational to our history as individuals, as cultures, as nations, as members of the community we call humanity. It is part of our fundamental being. In fact, as we well realize, the major advancements we have known in cultural history came about precisely because of unprecedented and totally unexpected transformations. Such transformations came into being because someone, somewhere desired enough to discover, invent, and innovate. And this took the courage to change. Such profound discoveries are truly *Supernovae*—quantum leaps that come into our lives unpredictably and without any prior preparation. This year, we can look back at many. Two come to mind.

Fifty years ago, in 1962, President Kennedy's newly inaugurated lunar space program was being launched from Cape Canaveral. Many of us remember well John Glenn's incredible earth orbit in February of that year. President Kennedy himself, later that same month, went to award Astronaut Glenn and Project Mercury Director Robert R. Gilruth with the Distinguished Service Medal of the National Aeronautics and Space Administration. The President had engaged the American nation in the race for the moon. He awarded those who had successfully aided the nation to take some of the first steps toward the ultimate goal. For our part, we became fascinated with achieving the impossible. The imagination of the nation was caught up in initiatives that made the seeming mythology of space travel become ever more real. It was a moment of quantum leap.

Then in October of the same year, the nearly 2000 year old Roman Catholic Church was catapulted into modernity by Pope John XXIII. The Second Vatican Council, only the second council in over 400 years, was the first time that this body's leadership came together not to battle modernity, but to embrace it so as to serve more faithfully the contemporary and future needs of women, men, and children of every race, nation, culture, and affiliation. Another quantum leap.

These two events of a half-century ago remind us of the immense energies and powers that are ever part of the non-negotiable experience of change, transformation, reform, and renewal in human history. Such events always break open in human experience and human history. It is our moral responsibility to develop an enthusiasm for the unknown.

This edition of the *Journal of Healthcare, Science and the Humanities* invites us to consider the alluring power of transformation in our lives, both personal and professional. We always stand like a young student many decades ago looking at images and early films of the darkness of outer space pocked with the brilliance of stars and spinning galaxies. We stand always in the potential moment where one star might burst forth in rebirth in the act we call *Nova*. I suggest that the primal space where we need to look today for this experience of the *Nova* is not outside ourselves. Rather it is within.

Where are we being called to transformation, reform, renewal, and rebirth in our own lives and in our service to those who come to us for human care? Where are we being called to become different? Where are we being called to be the *Nova*? Where are we being called "to become?"

It is to these questions that this edition of the *Journal* and its articles are dedicated.

May your sense of Human Desire lead you to enjoy the bursts within.

Prevention of Post Traumatic Stress Disorder among Military Health Care Workers: A Systematic Review

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Abstract

Studies indicate that Posttraumatic Stress Disorder (PTSD) is not uncommon among medical personnel serving in the military and that its prevention remains a significant challenge. While extensive PTSD research findings exist that are generalizable to the military, dedicated research specific to its at-risk population of medical workers is less common. The purpose of this review is to perform a systematic search for the most effective strategies in the prevention of PTSD and consider their applicability to the military healthcare provider. Comprehensive electronic search was performed utilizing MEDLINE, Cochrane Database, PubMed, CINAHL (EBSCO), Health and Wellness Resource Center, Nursing and Allied Health Source, Applied Social Sciences Index (CSA), PsycARTICLES (APA), and PAIS International (CSA). Significant variation exists among PTSD preventive strategies in effectiveness and in applicability to military healthcare workers. Strategies such as multiple early interventions, psychological debriefing, pre-deployment training and psychoeducation lack current evidence for efficacy in the prevention of PTSD. PTSD preventive strategies should favor therapy that identifies the traumatic event, with long-term outpatient therapy more effective than short-term inpatient. Vigorous physical exercise and unit cohesion are significantly associated with decreased odds of PTSD symptom development among military personnel. Awareness of significant risk factors may improve preventive outcomes by

enabling earlier intervention, and insights on resiliency may further optimize effective PTSD preventive strategies. Modified Prolonged Exposure (PE) therapy may be an effective and practical early intervention with expanded applicability to military operation settings.

Keywords: Posttraumatic Stress Disorder, PTSD Prevention, Military Healthcare Worker

Introduction

Given the risk for PTSD among military members deployed to combat settings, military health care providers are trained in its diagnosis and treatment. Despite this training, providers themselves are also susceptible to PTSD. Military medical personnel serving within active combat zones may face the dual challenge of treating severely injured service members and being personally subjected to life threat, and PTSD is not uncommon among them (Maguen et al., 2008). One study found that between 4.7 and 11.9 percent of military health care workers returning from recent deployments to combat settings met criteria for probable PTSD (Grieger, Kolkow, Spira, & Morse, 2007). Prospective longitudinal studies of PTSD among 355 military healthcare workers who cared for victims of an air disaster revealed a PTSD prevalence that ranged between 7.3 to 13.5 percent at the end of the 18 month study (Epstein, Fullerton, & Ursano, 1998).

Despite the prevalence of PTSD in studies among military health care workers, experts in the field who have examined emergency response worker PTSD note that there is limited literature examining early intervention methods, and that no particular model for this population of service workers has demonstrated clear efficacy (Eriksson, Foy, Larson, & Litz, 2004). With the added responsibility of military service, health care workers have the potential to face varied and perhaps additional stressors given today's fast-paced operational tempo in which war deployments and trauma exposure are not uncommon. While emphasis is often placed on PTSD diagnosis, treatment or prevention among nonmedical personnel, the purpose for this paper is to perform a review of peer-reviewed and evidence-based literature for post-traumatic stress disorder prevention strategies and consider their applicability to military health care providers. The aim is to address the research question "What are the best available practices and strategies to prevent PTSD among military health care providers?" A review of the literature with focus on finding effective evidenced-based prevention strategies potentially applicable to military medical providers would be invaluable at lending to the prevention of PTSD among such an at risk group of workers.

Methods

A comprehensive search was performed of MEDLINE, Cochrane Database, Pub Med, CINAHL (EBSCO), Health and Wellness Resource Center, Nursing and Allied Health Source, Applied social sciences index (Cambridge Scientific Abstracts), PsycARTICLES (APA), and PAIS International (Cambridge Scientific Abstracts) using the initial broad subject search "posttraumatic stress disorder or PTSD" and "prevention" for peer-reviewed and evidence based articles published between 1998 to 2011.

Inclusion criteria held that the study involve preventive strategies with either direct or potential applicability to the military healthcare worker. Given their duel role as service

members and as healthcare providers, studies involving both non-healthcare military service members, and non-military healthcare and emergency response workers were also included in order to maximize the capture of applicable PTSD preventive strategies. Papers not published in English were excluded from the review if no translation was available.

Results

While numerous strategies aimed at PTSD prevention exist, not all are equally effective. Many of these strategies fall into the realm of "psychoeducation." Psychoeducation is defined as information given to individuals about the nature of stress symptoms, both posttraumatic and other, and what to do about them. The aim of psychoeducation is to mitigate the effects of such exposure (Krupnick & Green, 2008). Although vast resources have been used to develop such programs, few studies examine the impact that educational briefings and stress control teaching has on incidence and long-term PTSD prevalence (Hourani, Council, Hubal, & Strange, 2011). Despite the common employment of psychoeducation as an intervention with the aim to prevent PTSD, researchers note a lack of clear evidence for its efficacy (Krupnick & Green, 2008; Hourani et al., 2011; Wessely et al., 2008). Among military members who received psychoeducation there was no significant difference among PTSD checklist scores when adjusting for all demographic variables (Greenberg, Langston, Fear, Jones, & Wessely, 2008). Certain PTSD preventive strategies that have generally been thought beneficial in this area may instead be ineffective, and some perhaps even harmful. For example, the widely employed population based strategy of military personnel pre-deployment training was found to be ineffective at PTSD prevention (Renshaw, 2011). In addition, Sijbrandij (2010) found that multiple session early psychological interventions after trauma do not prevent PTSD (Sijbrandij, 2010). In fact, trends exist for increased self-report of PTSD symptoms at 3 to 6 month follow-up studies following multiple interventions that occurred within 3 months after the traumatic event, and one trial reported that at one year there was a significantly increased risk of PTSD for those who underwent a single session psychological debriefing (Roberts, Kitchiner, Kenardy, & Bisson, 2009; Rose, Bisson, Churchill, & Wessely, 2002). Might those members be more attuned to the signs of PTSD and thus more likely to seek help/report to professionals? Although that seems possible it was not reported or concluded in the findings.

Researchers who report a general lack of evidence regarding the efficacy of psychoeducation have conjectured what good programs should resemble. They agree that programs that promote social support, facilitate appropriate help-seeking, and reduce stigma of stress reactions can foster improved coping and adaptation; and that fostering resilience, if able to be taught, would be useful (Krupnick & Green, 2008).

Other strategies show promise in regards to PTSD prevention. Research conducted on military personnel, not specific to medical workers, suggests that vigorous physical exercise and unit cohesion are significantly associated with decreased odds of PTSD symptoms (Leardmann et al., 2011; Brailey, Vasterling, Proctor, Constane, & Friedman, 2007). Researchers who studied over 700 Air Force medical personnel provided further evidence that unit cohesion serves as a protective buffer against PTSD symptom development, regardless of level of stress exposure (Dickstein et al., 2010).

Compared to short-term inpatient therapy, extended outpatient therapy after a significant traumatic event seems to be more effective (Tecic et al., 2011). When comparing target population based approaches, a collaborative care model appears more effective than a cognitive behavioral therapy (CBT) approach—therapy focusing on patterns of thinking and underlying beliefs that are maladaptive with emphasis on positive behavioral changes; and dissemination of a collaborative care broad reach prevention strategy may result in a 9.5 fold greater cumulative reduction in the incidence of PTSD compared to a CBT approach (Zatzick, Koepsell, & Rivara, 2009). Collaborative care models for PTSD involve symptom monitoring of those exposed to a traumatic event with subsequent case-manager adjustment and coordination of level of care (Feldner, Monson, & Friedman, 2007). While not specific to military medical workers or to preventive outcome measurement, it is relevant to note that one study involving the universal screening of over 4000 active duty service members with subsequent care facilitation where indicated concluded that the collaborative care approach is feasible in military primary care settings (Engle et al., 2008).

Also promising is the notion of identifying a causal event. The identification of a causal traumatic event may make prevention efforts for PTSD more effective and feasible than for other psychological disorders, and such interventions can be targeted at traumatized individuals who are beginning to show signs of acute stress disorder with the goal of preventing chronic PTSD (Sones, Thorp, & Raskind, 2011).

Early findings among pilot studies that implement both early outpatient therapy and the identification of a causal event have lead to the study of Prolonged Exposure (PE) therapy as an intervention that may be beneficial in the prevention of chronic PTSD, particularly among military settings. Prolonged Exposure is typically delivered in weekly 60 to 90 minute individual sessions over 10 to 12 weeks in specialty mental health clinics. Recognizing that this time intensive model is not always possible for active-duty military members often working long hours in austere settings, researchers studied a modified version of PE and cognitive processing designed for use within primary care settings instead of mental health clinics. Military service members diagnosed with PTSD were given a "Confronting Uncomfortable Memories" activity work book on the first 30 minute appointment designed to be completed at home and carried back for follow-up appointments. As part of this task, service members were required to write a first-person detailed narrative of the deployment event associated with the greatest level of current stress and preoccupation, including recollection of feelings, physical reactions, and personal thoughts. They were then asked to read the trauma narrative for at least 30 minutes each day and complete subjective unit of distress (SUD) ratings for self-monitoring of emotional reactivity. Fifty percent of those completing treatment no longer met criteria for PTSD at the 1-month follow-up assessment across four different outcome measures for PTSD—the PTSD Symptom Scale, Interview Version; the PTSD Checklist—Military Version; the Patient Health Questionnaire-9, and the Behavioral Health Measure ($p < 0.05$ for all) (Cigrang et al., 2011).

The concept of personal resilience traits that may be preventive for PTSD is often mentioned in the literature. Resilience can be defined as an ability to recover from negative and high stress experiences and ultimately find meaning in adverse situations through response flexibility in the face of situational demands that are ever-changing (Maguen et al.,

2008). More simply defined, resilience reflects an individual's ability to maintain relative stability in terms of mental function throughout the course of events (Bonanno, 2004). Being in a relationship, having fewer psychosocial difficulties, greater perceptions of purpose/control, and family support were significantly associated with resiliency among soldiers surveyed after return from combat deployments (Southwick, & Pietrzak, 2011). Among military medical personnel, correlation was found for two resiliency factors as protective for PTSD symptom development prior to deployment to combat environments: personal trait resilience, with positive affect the most strongly associated resiliency factor; and the presence of positive military experiences. However, the authors note that risk factors were more robust at predicting PTSD symptoms than were resiliency factors at predicting absence of PTSD symptoms (Maguen et al., 2008). Increase in resilience has been associated with extroverted and conscientious traits, and this correlation was found to be stronger among members of ethnic minority populations than for Caucasian groups (Campbell-Sills, Cohan, & Stein, 2006). Lower resilience scores have been found among individuals with lower levels of income and education, and individuals with history of childhood maltreatment (Campbell-Sills, Forde, & Stein, 2009).

Discussion

The aim of this review was to discern and discuss the best available practices and strategies for PTSD prevention among military health care providers. As anticipated, the majority of collective research regarding PTSD prevention is not specific to health care providers who are in the military, but instead is largely focused on either nonmedical patient populations, military-only populations, or healthcare-only populations. Valuable insight and understanding were gained from this literature review that may be applicable to PTSD prevention among military health care providers.

Conclusions and implications from this review are multifaceted. Certain strategies typically thought to be effective, such as multiple early interventions or pre-deployment training for example, do not seem to be effective. PTSD preventive strategies for military health care workers facing a significant traumatic event should favor therapy that aims to identify that event throughout the scope of long-term outpatient therapy as opposed to multiple session short-term early interventions.

Awareness of significant risk factors may enhance early intervention efforts and improve preventive outcomes. Extensive research has been conducted in search for reliable factors associated with increased odds for PTSD. The large majority of studies lack at minimum longitudinal cohort design and are rarely specific to the military medical worker, and therefore conclusions of association are more common than those that reliably conclude relative risk and serve as predictors for PTSD development. One exception is the prospective longitudinal cohort study by Epstein et al. (1998) which followed 355 military medical providers up to 18 months after having cared for the mass casualty victims of a large-scale air disaster; concluding that lower levels of education, exposure to grotesque burn injuries, stressful life events following exposure, and feelings of numbness following exposure are useful predictors of subsequent development of PTSD (Epstein et al., 1998). Another longitudinal prospective cohort study, not specific to medical workers but involving over 23,500 U.S. military personnel from among the Army, Navy, Marine Corps, and Air force

who had deployed in support of the conflicts in Iraq and Afghanistan, concluded that those with a history of one or more mental health disorders during baseline screening conducted between 2001–2003 had a statistically significant 2.5 times greater relative risk, and those with history of deployment-related personal injury while only a slight increase, were also statistically at greater relative risk of screening positive for PTSD in at least one follow-up screening conducted in either 2004–2006 or in 2007–2008 (Sandweiss, 2011). Cross-sectional studies that exclusively involve military medical workers have cited pre-deployment stressors and lifetime trauma exposure as factors associated with increased odds for PTSD symptoms prior to deployment; and one that administered anonymous surveys to military health care providers who had deployed to Iraq or Afghanistan found that direct threat exposure (frequent personal engagement in direct combat or being fired upon by opposition forces), perceived threat (frequent concern regarding being in danger of personal harm), and non-Caucasian race were associated with 17, 8.9, and 9.2 times greater odds, respectively, of meeting criteria for probable PTSD. Neither age, gender, educational level nor exposure to wounded or dead patients were associated with increased risk of probable PTSD (Maguen et al., 2008; Grieger et al., 2007). Among soldiers who served in combat environments risk factors for increased PTSD symptoms included lower post-deployment social support and lower unit support (Pietrzak et al., 2010). In a study involving over 22,000 Army soldiers during a 12 month deployment in Iraq, duration of deployment was associated with increased stress problems but not with sustained or substantial increase in mental health casualties (Warner et al., 2007). Meta-analysis not specific to military or to medical workers conclude that the following are risk factors for PTSD: history of mental illness, personal injury, living through dangerous events and traumas, seeing others injured or killed; feeling horror, helplessness, or extreme fear; having little or no social support after the event; and dealing with extra stress after the event, such as loss of a job, home or loved one (Brewin, Andrews, & Valentine, 2000).

From a broad based targeted population standpoint, future strategies aimed at preventing PTSD among populations of military health care workers may be more successful if they implement programs that promote routine vigorous physical activity. When accomplished together as a team, the added benefit of increased unit cohesion among military health care workers will also have a protective effect against PTSD. Since targeted population pre-deployment training has not been shown to be effective, consideration should therefore be given to enhancing the content of such training, while ensuring routine longer term regularly scheduled vigorous unit physical training for military health care workers, especially prior to deployment to combat settings. This is important to emphasize as all too often in the health care field, time for physical exercise is prone to being placed at a lower priority. Military medical leaders armed with the knowledge that both physical exercise and strong unit cohesion are protective against PTSD will have greater credibility and a stronger case for successfully implementing mandatory group physical training programs among their military health care workers, ensuring its part in the routine of the work day.

Modified Prolonged Exposure therapy offers unique applicability to military in austere settings. Although additional research is necessary, its translation into primary care settings, as well as its initial success, show promise for an effective and practical early intervention strategy that may be adopted in efforts to prevent PTSD among military health care providers.

More research is needed on PTSD prevention among military health care workers. Large scale prospective studies specific to combat medics, for example, are currently underway. The preliminary objectives of one such study—to assess the pre-existing behavioral health issues of combat medics and determine pre-existing risk factors to psychological resiliency and pre-existing protective factors of psychological resiliency—are encouraging (Maiers et al., 2011).

Scales used to measure resilience continue to evolve and numerous variations exist. Military publications acknowledge the lack of a 'gold standard' method for resiliency testing, but not uncommonly advocate or utilize the Connor-Davidson Resilience Scale (CD-RISC), the Response to Stressful Experiences Scale (RSES), Disposition Resilience Scale (DRS-15), and designed specifically for post-deployment testing, the Deployment Risk and Resilience Inventory (DRRI) (Watson, Litz, Southwick, & Ritchie, 2011; Maiers, Mayer, Baker, Escolas, & Chapman, 2011; Ballenger-Browning & Johnson, 2009; Maguen et al., 2008). In a review and comparative assessment of resilience measurement scales applicable to civilian populations, the authors concluded that they were unable to find a current 'gold-standard' among 15 separate resilience measurement scales; but that overall the CD-RISC, the Resilience Scale for Adults (RSA), and the Brief Resilience Scale received the highest ratings, and the DRS-15 well-ranked for fixed-trait resiliency testing (Windle, Bennett, & Noyes, 2011). Of note, Windle et al. (2011) did not include either the RSES or the DRRI in their assessment, perhaps due to the reviewers' background orientation to resiliency among civilian populations with emphasis on healthy aging (Windle et al., 2011).

The CD-RISC is a 25-item scale with total score ranging from 0 to 100, with higher scores indicating greater resilience; and validation of factors of personal competence, trust in one's instincts or tolerance of negative effects, positive acceptance of change, and control and spiritual influences (Ballenger-Browning, & Johnson, 2009; Connor & Davidson, 2003). Among soldiers who served in combat operations, those without PTSD had significantly higher resilience scores on all CD-RISC subscales, with the exception of spiritual influence which was not significant, compared to those with PTSD (Pietrzak et al., 2010).

The RSES is a 22-item scale initially validated exclusively in an active-duty and military reserve sample. Totals scores range from 0 to 88, and higher scores signify greater resilience. The RSES includes factors of positive appraisal, spirituality, active coping, self-efficacy, meaning/learning and acceptance of limits (Watson et al., 2011; Ballenger-Browning, & Johnson, 2009).

Modifications to the Dispositional Resilience Scale (DRS), developed over twenty years ago, have yielded a shorter 15-item hardiness scale (DRS-15) with the advantage of brevity, good internal and external validity, test-retest reliability of 0.78; as well as maintenance of reliability, validity, and cultural appropriateness among translated versions (Bartone, 2007; Hystad, Eid, Johnsen, Laberg, & Bartone, 2010). It is designed to measure psychological hardiness (commitment, control, and challenge); as regarded as a fixed trait; and has been used effectively to predict success among U.S. Army Special Forces candidates (Bartone, Roland, Picano, & Williams, 2008; Windle et al., 2011).

Increased large scale collaborative research that spans across all branches of military service are also encouraged, given the diverse roles that each service may assume in regards to trauma medical care and potential exposures. Such research will add to the foundation of identified significant resiliency factors and allow for efficient integration of screening and training programs intended to prevent PTSD among all military branches of medical personnel.

Once the factors that lend to protective resiliency specific to this population are identified, prospective randomized controlled trials may be conducted that implement those resiliency factors among dedicated training programs, or perhaps as screening criteria for such professions, and the outcomes would likely prove invaluable. Research that harnesses the coping styles of especially resilient personnel may offer ways of teaching those skills to others. Improved knowledge of the elements related to mental resilience can lead to enhanced training and clinical programs that optimize protective factors among military medical personnel; not only in day-to-day operations, but particularly before, during, and after combat deployments when stressors and potential traumatic exposures are at their highest.

Conclusion

Significant variation exists among PTSD preventive strategies in effectiveness and in applicability to the military healthcare worker. While current evidence is lacking for a single strategy that is efficacious in the prevention of PTSD among this population; improved awareness of factors associated with risk and with mental resiliency, combined with enhanced understanding and early appropriate implementation of effective interventions, may optimize PTSD prevention at both the individual and at the broad-reach population-based level for this at-risk group of personnel. Further research is needed for this common force health protection concern.

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From Intervention to Outcome:
The Relationship between Knowledge and Behavior
in a Trachoma Control Project

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Abstract

The fundamental problem for evaluating social health interventions is the relationship between the health promotion effort, behavior change, and subsequent disease outcomes. Trachoma, *Chlamydia trachomatis*, an infection of the eye, is the leading cause of preventable blindness in the world. Trachoma is hyper-endemic among the rural population of the Egyptian Delta. From 1990 through 1991 an Egyptian–American health intervention was conducted to increase the number of children who had their faces washed with soap and water at least once each day, a behavior known to reduce the risk of active infection.

The research design of this intervention allowed us to determine the levels of change in beliefs about the cause and possible prevention of eye disease, active and passive knowledge about face washing, and actual behavior change. The project demonstrated large changes in knowledge and attitudes resulting from the intervention. These changes indexed smaller changes in passive knowledge and still smaller changes in behavior. These small behavioral changes, however, were shown to be statistically significant in reducing children's risk in the target village, where the risk for active infection was decreased by a third.

Keywords: Trachoma, Behavior Change, Egypt, Intervention, Health Promotion

Introduction

Health education, leading to the adoption of healthier behavior, is perhaps the most frequently used model of public health promotion. Despite its popularity, the relationships among knowledge, attitude, behavior and disease reduction are not fully understood. The transtheoretical model developed by Prochaska and his colleagues (Prochaska & Velicer, 1997) moved the understanding of these relationships forward by setting out stages through which individuals move from pre-contemplation to enacting the behavior. Contemporary neuroscience and psychological studies have addressed the link between knowledge and behavior by analyzing motivation, such as presented in Jonah Lehrer's (2009) book, *How We Decide*. But, as a host of recent studies attest, behavior change interventions are fraught with difficulties in moving from imparting knowledge to changing the outcome of the disease or condition under study (Boden-Albala, Carman, Moran, Doyle, & Paik, 2011; Gkeredakis et al., 2011; Heinrich, Maddock, & Bauman, 2011; Owens, Jones, & Nash, 2011; Stuart et al., 2011; Sun et al., 2011; Takemura et al., 2011). Many of the cited studies beg the question of disease change altogether by claiming success through changed intentions, or changed risk perception.

Evaluations of health interventions can more directly ask a set of four questions with regard to measuring the change in disease prevalence: Can it work? Does it work? How does it work? Is it worth it? (Bartholomew, Parcel, Kok, & Gottlieb, 2001; Cochrane, 1972; Haynes, 1999). Changing individual or group behaviors are the main goals of many health interventions. Some consider behavioral change the "central outcome" of health interventions, especially in primary prevention (Kaplan, 1990, 2000).

Answers to the question, "Can it work?" can be found in theoretical analyses, from preliminary empirical observations, or both. By showing that changes in the epidemiology of a disease result from the intervention, a carefully designed, community-based health intervention can answer the question, "Does it work?" (Shadish, Cook, & Campbell, 2002).

Answers to the question, "Is it worth it?" depend upon a variety of practical, financial and political considerations that factor into decisions as to whether or not to use a proven intervention on a broad scale.

It is much more difficult for interventions that seek to change health related behaviors to answer the question, "How does it work?" (Øvretveit, 1998). Assessing behavior change outside of the laboratory can be very difficult, as appropriate evidence is sometimes

impossible to gather, or can be gathered only indirectly (Michie & Abraham, 2004: 36). Moreover, "proper interpretation of the evidence depends on the availability of descriptive information on the intervention and its context" (Rychetnik, Frommer, Hawe, & Shiell, 2002:119). Behavior change is especially difficult to assess because the evaluation data can often only be obtained from self-reports or other indirect proxy measures. This makes it especially difficult to know whether any behavior change or outcome attributable to the intervention, including any the theoretical models of change on which the intervention was based, is truly responsible for that change.

This paper looks at the relationships among knowledge, attitude, and health outcomes in a study of trachoma in the Egyptian delta. A logistic regression analysis, which controlled for the seasonal variation of eye disease, showed that the intervention over one year was successful in reducing the risk for active infectious disease among children in the intervention village by a third (OR = .675, 95% CI .460, .989, p = .043. The intervention was developed based on ethnographically-derived, culturally-valued health behaviors in the community (Lane, 1987), and using local cultural materials.

The findings of this study, together with other similar studies of face washing, and studies of oral azithromycin for the treatment of trachoma (e.g., Dawson et al., 1997), formed the basis of the SAFE strategy (surgery, antibiotics, facial cleanliness, environmental improvement) used by the International Trachoma Initiative's strategy to eliminate blinding trachoma by 2020.

The intervention design and results are presented in detail elsewhere (Rubinstein et al., 2006), but before turning to examine the relations among self-reported behavior change and observed behavior change in the intervention, it is useful to provide some background context.

Face-Washing and Trachoma

Trachoma is a chlamydial infection of the eye and is the leading cause of preventable blindness in the world. Recent estimates indicate that trachoma is "responsible for 1.3 million cases of blindness … [and] is endemic in 55 countries, mainly in Africa and Asia" (Polack et al., 2005:913). Infection with the bacterium *Chlamydia trachomatis* leads to inflammation of the upper eyelid. Clinical diagnosis of active trachoma is made following detailed World Health Organization criteria in which the inner upper eyelid is examined under ×2.5 magnification. The clinical severity of trachoma is graded according to the number and size of follicles observed on the conjunctiva and the inflammatory thickening of the tarsal conjunctiva (Bird et al., 2003:1670). Those infected by *Chlamydia trachomatis* do not develop immunity to the organism, and thus can be re-infected, perhaps multiple times. Following active infection, scarring of the conjunctiva results when the follicles and swelling resolve. Active infection and inflammation can lead to permanent conjuntival scarring. Severe and repeated scaring of the eyelid can make the inner eyelid contract and turn inward, causing the eye lashes to rub against the cornea. Overtime, this painful condition can also cause the cornea to become opaque, resulting in loss of visual acuity, eventually leading to blindness.

Active trachoma infection is seen mostly among children. For example, in the Egyptian Delta, research showed that the prevalence of trachoma among the population

declined sharply after children reached fourteen years of age. Although active infection is largely a disease of childhood, the scarring and blinding consequences of trachoma infection mainly affect adults.

In conjunction with on-going United States–Egyptian research on blinding eye disease in the Egyptian Delta, Sandra Lane conducted ethnographic research on eye disease in a Delta hamlet. During this work, she made systematic observations of a sample of households that indicated that children that had their faces washed once a day with soap and water were at considerably reduced risk for having active infectious trachoma (Lane, 1987: 179–201). In contrast with other studies (e.g.,Taylor, Velasco, & Sommer, 1985), only face washing with soap and water (as opposed to with water alone) provided a protective effect.

In addition to these empirical observations, there were convincing theoretical reasons to think that community-wide efforts to promote face washing could change the epidemiology of trachoma. Theoretical models of trachoma transmission based on animal and human studies (Forsey & Darougar, 1981; Salim & Sheikh, 1975) suggested that flies formed an important vector for the transmission of trachoma, especially in environments that lacked basic hygiene infrastructure (e.g., Courtright et al., 1991), because they spread the occular secretions from eye to eye.

But, would promoting face washing on a community-wide basis work more broadly to decrease active infectious trachoma? To answer this question, the Francis I. Proctor Foundation of the University of California, San Francisco in collaboration with the University of Alexandria Medical School, and the High Institute of Public Health, in Alexandria, Egypt, proposed to demonstrate the efficacy of a community-based health intervention to promote face washing. We integrated the standard Knowledge, Attitudes and Practices (KAP) measures (see, e.g., Manderson and Aaby, 1992) into a data collection form that also drew on anthropological interviewing techniques and Lane's insights into the ethnomedical ideas about eye disease in the Egyptian Delta. Further details of these materials and of the research design of the intervention are available in Rubinstein, et al. (2006).

Prior to undertaking the intervention, a survey was made of villages in the Delta. The project epidemiologists and ophthalmologists visited a dozen villages during which they surveyed the environmental context of the villages and screened children for trachoma. All children diagnosed with trachoma infection were treated. The villages, which were all small communities (approximately 1,500 individuals) related to a larger administrative town, were included in the survey if they had roughly equal sized populations, similar access to water, and similar socioeconomic levels of development. We used this survey to identify four villages for the study. There were no statistically significant differences among the four in their environmental circumstances, size, socioeconomic status, and background rates of eye disease. One village was used as a setting in which researchers were trained and tested their research instruments. For the other three villages to be used in the study, we conducted in depth environmental surveys which allowed us to compare villages on a wide variety of environmental variables. After this environmental assessment we conducted statistical analyses to ensure that the villages were comparable on environmental factors that might affect eye disease. The three villages selected for the study showed no statistically significant differences on the environmental factors.

From the environmental surveys, we can characterize the villages in the following ways: All of the villages were farming communities without running water piped to the homes. Rather, each village had a common standpipe from which villagers could draw water. All adjoined canals the water from which villagers used for a variety of activities, including dishwashing, laundry, bathing and recreation. The walls of the houses in the villages were largely constructed of concrete brick while the floors of the houses were packed dirt. The houses typically had one or two rooms for use by the family, and nearly all of the houses in each village had an attached animal room in which the family's large animals could be kept. Animal manure is an important source of cooking fuel in the Delta and large dung piles are owned by families and kept near their homes. Although homes were built near one another, the villages had open public spaces and spaces between houses.

Statistical analysis of the pre- and post-intervention data controlled for seasonal fluctuation of eye disease. We also controlled for the potential bias of "Hawthorne effect" (see also, Shadish, et al., 2002; Wolfe & Michaud, 2010) by having a two intervention villages: one village with an intervention aimed at increasing face washing with soap of children and the second village in which an intervention of equal effort, but focused on activities that would not affect trachoma, were conducted. At the start of the study, children in the two intervention villages and the control village were examined by ophthalmologists, who diagnosed those with trachoma. There were no statistically significant differences among the three villages in the proportion of children with trachoma infection; all children in the three villages with trachoma infection were treated. At the end of the one year intervention period, the village with the face washing showed one third fewer trachoma infections among children, compared with the "Hawthorne" village. Thus, the community-wide face washing intervention reduced risk of active infectious trachoma by a third.

Measuring Knowledge and Behavior

The behavioral change that the intervention sought to promote was at least once daily face washing with soap and water of children aged 10 and younger. The intervention promoted face washing, and the risk of active infection declined. It is reasonable to interpret the decline in active trachoma in the intervention village as the result of behavior changed by the intervention. But, we wanted to know in greater depth exactly how this success was achieved.

The pre- and post-intervention questionnaires we used elicited self-reports about three different kinds of knowledge, attitudes and practices. We call these "passive knowledge," "active knowledge," and "specific beliefs," each which we discuss below. In addition, the study design included direct observation of face washing behavior among a systematic sample of households in the intervention village, the "Hawthorne" dummy intervention village, and the control village. This allowed us to examine how the reduction in active infection was achieved.

Knowledge Self-Reports

For the pre- and post-intervention questionnaires we used a basic ethnographic interviewing technique that invites the person interviewed to define the range of information to be considered. In our intervention study, the interviewer asked each mother, "What kinds of problems can happen to your eyes?" This kind of question, which is referred to in the anthropological literature as a "Grand Tour" question (Spradley, 1979: 62), allows an

open ended response, and gives the person interviewed a chance to use their own knowledge to outline the domain. In our intervention this question invited the enumeration of any ethnomedical eye problem. Our questionnaire form included space for a dozen ethnomedical eye conditions that had been described by Lane (1987) in her health ethnography, as well as opportunity for other volunteered responses.

Any eye condition elicited through the grand tour question required that the mother being interviewed volunteer this knowledge. Because her response was unprompted, we call the information elicited through the grand tour question an instance of "active knowledge." Active knowledge is a report by the informant of some aspects of her world that are salient to her, without prompting.

Specific Beliefs Regarding Behavior

Ethnographic interviewing techniques also include in question frames that elicit smaller domains of knowledge. These kinds of questions, which are called "Mini Tour" questions, ask "an informant to describe some smaller unit of an event or activity" (Spradley, 1979: 63). Such questions also elicit active knowledge, but the information elicited is about a restricted range of information. During the interviews, we asked mothers to respond to two mini tour questions that described their belief and behavior about face washing. These questions "How many times per day should children's faces be washed?" and "With what should children's faces be washed" give us information about specific practices that mothers self report.

Passive Knowledge

The very last question asked by our interviewers was "Have you ever heard of trachoma?" (The actual question was "Have you ever heard of Ramad Hubaybi?" Ramad Hubaybi is the Egyptian Arabic medical term for trachoma.) Since the response to this question required no active response on the part of the mother being interviewed, the answer to this question represents a relatively passive pool of information. For this reason we call this "Passive Knowledge."

Observed Behavior

It is something of an anthropological truism that what people say they do and what people actually do are not always the same. Indeed, systematic studies of informant accuracy "show that informant reports of behavior are incorrect about half the time, but that the distortions are highly patterned" (Trotter II & Schensul, 1998: 719). When Lane (1987) interviewed families about face washing of children with soap and then conducted direct day-long observations in the same families she found that there was approximately 28% difference between what mothers reported doing and what they were observed to do. The uncertain accuracy of self-reported data is a problem faced by epidemiology as well (Hulley, Cummings, Browner, G., & Newman, 2007: 43). The bias inherent in informant recall, and the frequent disparity between normative and actual behavior, means that during fieldwork anthropologists gather information about what people do through a variety of methods and measures. This practice, which is an example of "triangulation" (Rubinstein, Scrimshaw, & Morrissey, 2000; Trotter II & Schensul, 1998), resonates with Campbell's and Fiske's (1959) advice for increasing validity in quantitative research design.

For this reason, the data collection for our intervention study included two periods of direct observation of face washing behavior. For these "observational family studies" a researcher observed the children in 15 households. The researcher, who was trained in systematic observation of behavior (Johnson & Sackett, 1998), spent six hours in each household during which she used the time allocation method to count the instances of children having their faces washed with soap and water. This allowed us to cross-check reported behavior with actual behavior.

The Face Washing Intervention

The face washing intervention took place over one year. During that time the face washing intervention village received information about trachoma and face washing through several modalities (for details of the intervention see, Rubinstein, et al., 2006).

Families with children 10 years and younger received periodic visits from local community health workers. These visits were more frequent during the early part of the first months of the intervention than during the rest of the year. During these visits health workers conveyed information about trachoma and its transmission.

The community health workers distributed bars of locally produced, and inexpensive, soap to families with children 10 years and younger on a bi-weekly basis. Soap distribution took place throughout the year-long intervention (Figure 1).

Posters encouraging face washing were posted strategically throughout the intervention village. These posters were hand painted in a style that mimicked the genre of local cinema advertisements, which earlier research had suggested would be effective in conveying other kinds of messages to the villagers.

A song patterned on standard folk melodies was created. This song described the transmission and effects of trachoma, and encouraged face washing. The song was taught to school children. During the intervention year, singing the song when community health workers or the project researchers visited the village became a kind of competitive game for the village children.

The final part of the intervention involved the creation of a puppet show about trachoma and face washing. This puppet show was patterned on a traditional cultural way of spreading news (and often political messages) called an *arragoz*. The puppet show was presented to an assembly of school children and their families.

How the Intervention Achieved Success

We were interested in knowing how the intervention achieved its success. To trace the effects of the intervention we analyzed the changes that took place in each of the categories of information we collected through our questionnaires and observations.
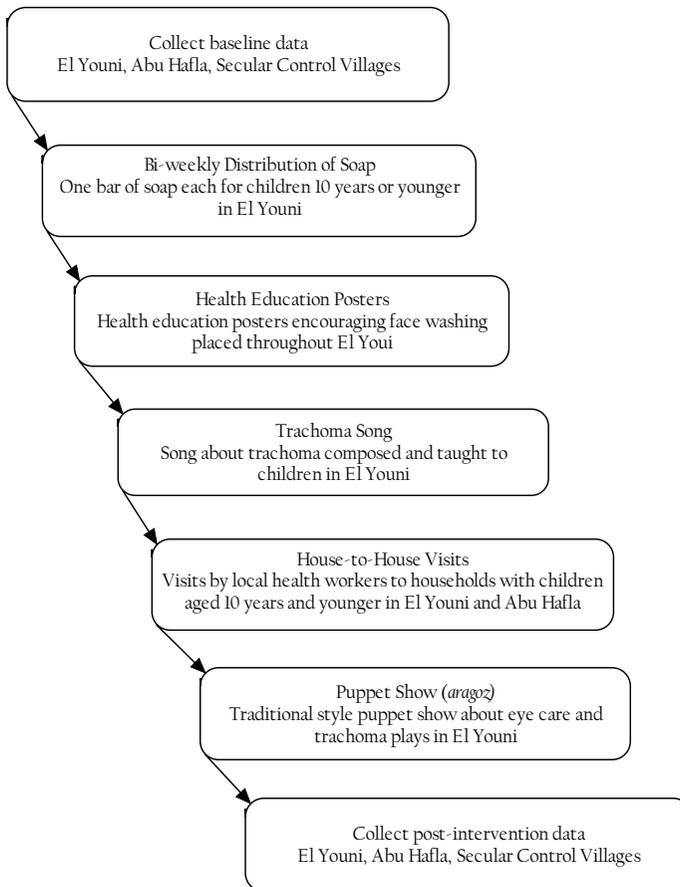
Figure 1. Elements of the Community-Based Face Washing Intervention

Passive Knowledge

Prior to the start of the intervention there was no statistical difference in the proportion of villagers who reported knowing the term *ramad hubaybi*, the Egyptian Arabic term for trachoma. After the year-long intervention the "Hawthorne" villagers' knowledge of the term had not changed, while 100% of the intervention village participants reported knowledge of the term (X^2= 206.72, p < .0001). Of course, the intervention village experienced a frequent, multi-faceted, and year-long effort to increase knowledge of trachoma, so the dramatic increase is understandable.

Active Knowledge

When asked "What kinds of diseases can happen to your eyes?" less than one percent of respondents in either the intervention or "Hawthorne" village volunteered *ramad*

hubaybi. At the end of the intervention, no one in the "Hawthorne" village volunteered r*amad hubaybi*, whereas 89% of those in the intervention village spontaneously mentioned the term ($X2= 207.99$, p < .0001). This finding indicates that *ramad hubaybi* was on the minds of those in the intervention village, at least when they were being interviewed by the research team (Figure 2).
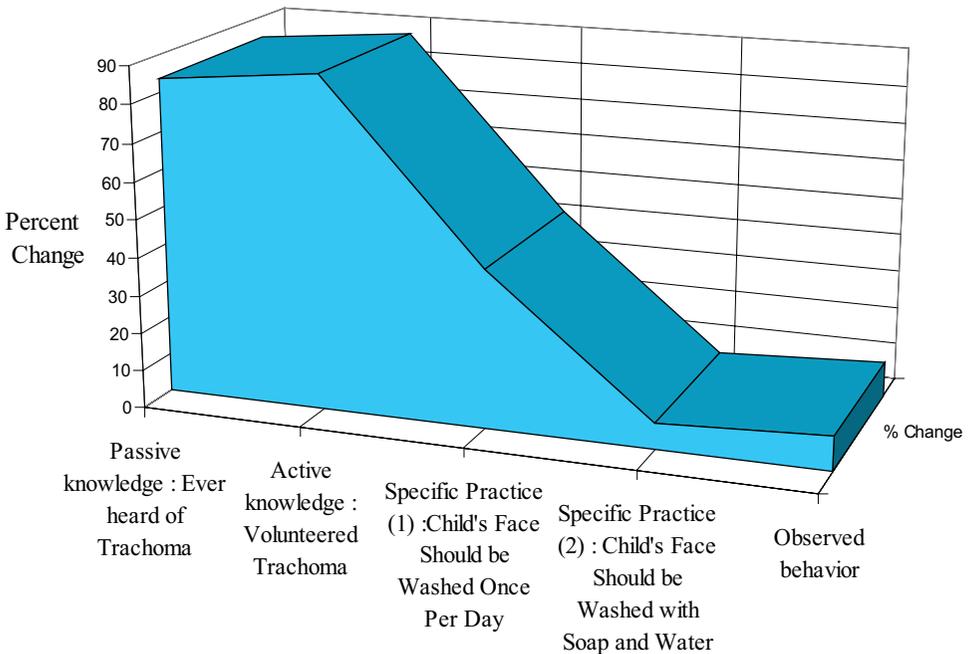
Figure 2. Change in Knowledge and Behaviors Attributable to the Face Washing Intervention

Specific Beliefs Regarding Behavior

When asked "How many times per day should a child's face be washed with soap" there was no difference between the answers of intervention or "Hawthorne" villagers prior to the study. At the completion of the study, the proportion of the intervention villagers whose responses specified the optimal number of face washings for children had increased by over 42% ($X2= 65.44$, p. < .0001), whereas the "Hawthorne" group had not changed.

Observed Behavior

In the observations conducted among families prior to the intervention no child face washing was observed in either the intervention or "Hawthorne" village households. In the observations at the end of the study still no children's faces were observed being washed in the "Hawthorne" village. In the intervention village, 9% of the households children were observed having their faces washed with soap ($X^2= 4.34$, p = .037). This is a relatively small change in behavior given the large changes in passive and active knowledge.

It may be that the six hour window of observation was inadequate to see all face washing. In Lane's study, she conducted observations from prior to sunrise, when the children were still asleep to after dinner, when the families were getting ready to retire for the evening. Even so, we were surprised to find that so much knowledge change had resulted in so little observed behavioral change.

Conclusion

The intervention's success derives in part from the careful attention paid to the local cultural understandings about health in general and eye disease in particular. By incorporating these understandings into our KAP instruments we were able to design intervention activities that addressed trachoma in terms that resonated with the people to whom the intervention was directed. The intervention drew on several aspects of Egyptian culture, including film posters, song, puppet shows, and used locally available soap. The messages in each of those media were clear, consistent, and advised a specific practice ("children's faces should be washed with soap at least once per day") that could easily be accomplished. Those two points are critically important. It was clear from the feedback of villagers to the research team that they were amused by the children singing the trachoma song. The response to the puppet show was also warm and enthusiastic.

During the time of this intervention, there were numerous 30 and 60 second spots on Egyptian television advertising oral rehydration solution (ORS), to prevent childhood death from the dehydration that accompanies diarrhea (Lane, 1997). Similarly, the televised ORS spots had a song that ran with each spot. In both cases, however, a curious disconnect emerged. People who could sing the jingle—of the trachoma song or the ORS commercial—did not necessarily follow through with enacted behavior.

Our trachoma intervention changed knowledge dramatically, by nearly 100% for the term *ramad hubabyi*, a least as measured directly after the one year intervention. It also appears to have changed ideas about normative behavior, which is what people say that they should do. In interviews at the end of the intervention, overwhelming numbers of intervention villagers told the research team that children's faces *should* be washed with soap and water. Many even enthusiastically increased the proposed number of face washings, above that recommended by the intervention, to more than three times per day.

But when it came to actual behavior—the observed face washing of children with soap—the increase was much less. This common and frustrating finding stymies health educators, who reflect on, for example, the paradox of people who know that smoking is dangerous but who nevertheless take up smoking or those who know unprotected sex with a potentially infected partner can hurt them nevertheless fail to use a condom. *Knowledge itself does not always, or even frequently, lead to healthier behavior*. A famous study by Young (1981) called attention to this apparent disconnect. Young's study, titled "When rational men fall sick…" pointed out that we are not machines or, in modern terms, computers. Human behavior is motivated only in part by knowledge processed in the rational pre-frontal cortex of our brains (Lehrer, 2009). Other, less logical but more compelling sources of behavioral motivation arise from our emotional limbic systems that spew out desire, lust, anger, fear and envy. In this regard it is important to understand that there was a competing reason why

some parents kept their children's faces dirty (Lane, 1987), the cultural belief that envy that in the form of the evil eye can be a source of illness and death, as we discuss below.

Even though the intervention led to a large change in knowledge and specific beliefs about behavior, it led to relatively little actual behavior change (although the change that did take place had very important consequences). While such an outcome if consistent with findings from other efforts to change health behavior, as discussed above, there are some aspects of the Egyptian Delta villages that may help account for this finding.

All of the villages in the intervention study were farming communities. During the rainy season the villages are muddy and wet, while at other times they are dry and dusty. Thus, children's faces get dirty quite easily and keeping them clean is a chore, especially when clean water has to be retrieved from a common standpipe some distance form one's home. Keeping children's faces washed and clean can become a time consuming activity in a day filled with other work and obligations. This may be a negative reason for the small observed change in actual behavior.

Cultural understanding helped the intervention to succeed. At the same time, cultural beliefs may account for the small change in observed behavior. Dirty faces spoil the appearance of otherwise beautiful children, whose beauty might attract the *evil eye*, which is the covetous glance of an envious person. The evil eye is an important cultural category and disease explanatory concept for Egyptian villagers. The evil eye is considered as the possible source for all sorts of calamity, including illness. Villagers go to considerable lengths to avoid attracting the covetous attention that might lead to being the subject of the evil eye. It might be that some villagers in the post-test interviews were telling the research team what they wanted to hear, "yes we know that you think that face washing is important—we have been hearing you say so for a year." This would be then a case of the patterned distortion of self-reports noted by Trotter and Schenshul (1998). But when a researcher was present in the home for observations, looking closely at the children only 9% had their faces washed. We think of direct observation as the "gold standard" for documenting behavior, but even this measure may be biased in ways that we cannot always predict.

Despite this small change in observed behavior, the intervention village showed a 33% reduction in infection after a year. In a sense, this result may be an example of the workings of the "Pareto Principle," which posits "that a small number of causes is responsible for a large percentage of the effect, in a ratio of about 20:80" (Hafner, 2001: para 2; first suggested by Vilfredo Pareto in his study of wealth distribution, see Pareto, 1964 [1896]). In our case, a year-long health education intervention yielded modest observed changes in behavior, but rather large changes in disease prevalence. This finding is similar to that of the Egyptian diarrheal disease control program, which found that diarrhea deaths were cut in half despite numerous studies that demonstrated that ORS was not appropriately used. We can only speculate on what happened. Perhaps, with the distribution of free soap and the health education about the links of blinding eye disease with face washing there was more face washing than we observed. Possibly, the families whose children had red and runny eyes did the most face washing. Nevertheless, a small behavior change resulted in larger than expected disease change.

Consistent with earlier findings concerning health behavior change, the face washing intervention produced large changes in knowledge and attitudes and much smaller changes in actual behavior. The reasons for these observations may be broadly applicable to other intervention efforts. On the one hand, barriers to health behavior change may result from potential environmental barriers to that behavioral change, and, on the other hand, culturally validated reasons for not changing health behavior may limit the change that takes place. In our own research we are incorporating designs which allow the parsing of these two types of barriers to change (e.g. Lane et al., 2008). A broad range of health interventions should give consideration to designs that allow researchers to map both the constraints on behavior change that result from structural barriers and those that are motivated by the social and cultural contexts in which they take place. Such designs can produce data that may then be used to revise interventions to emphasize areas that promote success in changing behavior, thus making them more effective.

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Identifying Ethical Issues in Healthcare

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Abstract

Healthcare administrators have an obligation to ensure that ethical practices are followed in the treatment and service of patients. In the patient service environment, administrators are often forced to balance the needs and interests of the patient, the organization, and society (American College of Healthcare Executives, 2007). As such, this process involves moral standards, such as justice, autonomy, beneficence, and fairness (American College of Healthcare Executives, 2007). Today's healthcare environment is ever changing and complex. Healthcare professionals are constantly faced with the challenge of balancing organizational goals with patient needs and societal demands. Future healthcare leaders must possess the ability to accurately and effectively make decisions under the most confounding of circumstances. It is critical for healthcare educators to facilitate healthcare management students' ability to apply ethical standards when faced with professional ethical dilemmas. In order to teach students to identify ethical dilemmas, it is first important to understand which factors typically enter into students' decision-making processes. The study explores the decision-making processes undertaken by graduate healthcare management students when presented with real-life practice scenarios.

Keywords: Ethical decision-making, Ethics, Healthcare Management

Introduction

The authors sought to analyze the ability of graduate healthcare management students to respond to ethical issues. The authors hypothesized that students would be able to identify ethical dilemmas embedded within two case-based scenarios, and make decisions in accordance with professional ethical codes. The authors presented the two case scenarios to twenty Masters of Healthcare Management students attending the Marymount University in Arlington, VA. Students were asked a series of questions designed to analyze the following factors: 1) Are students able to identify ethical dilemmas? 2) What decisions do students make when presented with such dilemmas? 3) How are decisions reached? and 4) Are ethical standards considered in the decision making process?

Cases and Surveys

The authors presented two cases to graduate health care management students. The first case detailed the ethical dilemma of a nurse who chose to act out of her scope of practice by administering medications. The second case presented a scenario involving a psychiatrist who prescribed "off-label" medications (i.e., prescribed drugs for purposes different from those indicated and approved by the FDA). Factors to be considered in reviewing both cases included: 1) health risk to the patient; 2) staff and patient autonomy; and 3) fairness and justice. Both cases were adapted from real-life dilemmas occurring in two different healthcare facilities. The cases listed below are the exact cases that were distributed directly to the students.

The authors were interested in how students considered ethical, emotional, and regulatory standards when making decisions. In order to assess these factors for each case, the students were asked to complete two surveys (See Appendix A and B). Each survey consisted of 3–4 open-ended questions and 3–4 yes/no questions. Students also had to complete a chart rating the factors considered in their decision-making, with each series of

factors grouped into subcategories to facilitate review. Students rated each factor on a 4-point scale coded 0 (*did not consider*), 1 (*less important*), 2 (*somewhat important*), and 3 (*extremely important*). All students had one hour to review the cases and complete the surveys. Results were tallied and analyzed for patterns and themes.

Case #1

West Queens Hospital is a small private hospital in a rural setting. For a small hospital, West Queens has a considerably busy emergency department (ED). The manager of ED is a Registered Nurse who also has her Bachelor's Degree in nursing. She is a very well liked manager, who does a good job with staff and patients. The executive committee has recognized her for her leadership skills.

There is a team environment and approach throughout the hospital. Staff often reference that they are part of a "family." However, the climate has changed recently. As a result of cutbacks, the hospital was forced to lay off several clerical staff members. One of the previous ED clerical staff comes to the hospital a month after she has been let go. Her insurance policy has elapsed and her husband has also recently been laid off from his job. They have two school-age children and a three-month old infant. All of the children are due for their current immunizations, which include:

1. Diphtheria—a respiratory tract infection, which can lead to breakdown of the central and peripheral nervous system.

2. Polio—a viral infection causing infantile and childhood paralysis.

3. Rotavirus—a bacterial virus that may eventually lead to dehydration and possibly death.

4. Homophiles influenza Type B—an invasive disease associated with pneumonia and meningitis.

If she does not get the children immunized, they will not be able to begin the school year. In addition, she is very worried about the baby, who has missed her two-month immunizations. Oddly, there have been two cases of rotavirus in the apartment complex where the family lives. In her concern, she approaches the ED manager and asks her to administer the shots. The manager explains that this would be beyond her scope of practice and that the children first need to be seen by their family doctor, who can authorize the immunizations. The woman explains that she does not have the money to pay out of pocket for these expenses. The manager informs her to try the community center; however, the community center is over two and a half hours away from where the woman lives, and she does not have transportation to get there. Still the manager explains that she is very sorry, but she cannot give the shots.

A half hour after this encounter, the manager is making rounds before her lunch break and notices one of her nurses sitting with the woman and her children in an exam room. It appears that the nurse has given the vaccinations to all of the children. The nurse, who has not had any other punitive action taken against her in the past, is fired on the spot.

Case #2

A psychiatrist is treating a 34 year-old highly educated, professional male for bipolar or manic depressive disorder. The patient has a supportive wife, who is very involved in his care. They have two young children.

The patient has been on the same course of treatment over the past 4 years. However, over the past 6 months, the patient has been experiencing frequent severe depressive episodes. The patient's wife recently read about a somewhat experimental usage for a drug, Cotraxen, which is normally used to treat anxiety disorders. The FDA approved dosage for the treatment of depression is 5 mg once a day. However, if taken at a higher dosage and frequency, there is evidence that drug may be effective in the treatment of bipolar disorder.

The patient and his wife present this information to the psychiatrist and ask for a prescription of Cotraxen. The psychiatrist speaks to his Cotraxen pharmaceutical representative, who informs him that it is true that the drug may be effective in the treatment of bipolar disorder. He also mentions that the drug's side effects may include agitation, seizure, and increased manic episodes. **Note:** *the authors recognize that off-label usage of drug therapies (using a drug for a purpose different from those indicated and approved by the FDA) is permitted by law. However, the marketing of these therapies beyond the FDA approved indications is illegal. We are asking you to address the ethical issues/decisions (not the legal issues) concerning each person in the scenario.*

The psychiatrist relays this information back to the patient and his wife. The patient is aware of the risk, but would like to try the treatment. The psychiatrist prescribes Cotraxen to the patient. The patient takes the medication as prescribed by the doctor. Three weeks into treatment he suffers a severe manic episode and is hospitalized.

Results

Based on previous classroom interactions, it was anticipated that 90% of the graduate healthcare management students would be able to appropriately identify the ethical dilemma presented in each of the two cases. We also expected variability in student approaches to decision-making, particularly in terms of how decisions were made and what factors considered during the decision making process. Furthermore, we anticipated greater variability in the application of ethical standards to the second scenario presented.

Case #1 Results

With regard to Case #1, we anticipated that students would be able to identify an ethical breach on the part of the nurse. While the authors recognize that a violation of healthcare regulations and standards does not always indicate a direct ethical violation, the nurse did act out of her scope of practice when she administered the drug without a doctor's order. Of the students polled, 80% recognized this ethical breach. Furthermore, of these students, 75% rated the scope of practice factor as *extremely important* in their decision-making.

The factor most frequently cited by students in the consideration of this breach was the health risk to children if they did not receive the appropriate immunizations. Sixty

five percent of the students rated this factor as highly important to their decision-making. Students weighed the decision heavily upon the perceived moral obligation to the children.

It was also intended in Case #1 that the students would recognize that there was not an ethical breach on the part of the manager. The manager acted ethically when she responded by terminating the nurse. The survey results showed that 55% of the students responded as was predicted. Of the 45% who perceived a breach on the part of the manager, 89% rated ethical leadership as either *extremely* or *somewhat important* when considering the manager's actions.

When asked if the manager complied with healthcare regulations and professional standards, 90% of the students responded that she was in compliance. Yet, many students (45%) perceived a breach on her part. The authors attribute this contradiction to emotionally charged decision making on the part of the students. To further support this interpretation, we note that most students did not consider the nurse's prior employment history. Consideration of the employment factor aligns with professional and organizational requirements that are ordinarily considered as a basis for determining employee corrective actions.

Responsibility to the patient was the most common factor mentioned by students in the evaluation of the manager's behavior. Of the students polled, 100% noted that this factor was either *extremely important* or *somewhat important* in their decision-making. Students saw the healthcare manager as having an ethical obligation toward the patient. This factor carried a great deal of weight in determining how students judged the actions of the manager. This held true for the majority of the students, regardless of whether or not the students identified an ethical breach on the part of the manager.

Case #2 Results

It was anticipated in Case #2 that a majority of students would be able to recognize an ethical breach on the part of the pharmaceutical representative. As noted in the scenario, off-label marketing of drugs is illegal. The pharmacy representative acted out of his scope of practice when he informed the doctor of the off-label usage of the drug. Furthermore, the pharmacy representative did not include pertinent information about the side effects of the drug when utilized out of the intended usage. This omission, whether deliberate or not, was unethical.

Only 25% of the students identified a breach on the part of the pharmacy representative. Overall, regardless of whether or not a breach was recognized, 90% of all students rated the non-disclosure of information on side effects as *extremely important* in the decision-making. This factor appeared to weigh heavily in the students' decision making, perhaps because the students perceived a strong moral obligation on the part of the pharmacy representative. Students believed that the representative had a moral obligation to protect patients of all side effects even for off-label use of the drug.

The authors anticipated that students would recognize that there was not an ethical breach on the part of the psychiatrist. The doctor acted within his scope of practice and in the best interest of the patient when he prescribed the medication. As anticipated, a majority of students (65%) indicated that there was not a breach on the part of the doctor. The

major factor in the decision-making, regardless of whether or not a breach was perceived, was the health risk to the patient. Eighty-five percent of the students rated this as *extremely important*, which is indicative of the students' tendency to weigh such factors more heavily than regulations and professional standards when making decisions. This information further strengthens the authors' argument that healthcare students assign greater weight to moral and ethical factors than to regulatory factors when determining ethical judgments.

Practitioner Application

The graduate students in this article addressed ethical issues in two cases that were presented in a classroom environment. It was interesting that the students most frequently based their decision-making on moral obligations. Such obligations are based on an individual's life experiences and not necessarily an organization's code of ethics or ethical standards of behavior and practices.

Appropriately identifying ethical dilemmas and taking corrective actions will be undermined if personal and professional standards are not properly aligned. Healthcare professionals, who primarily base their decisions on a case-by-case basis, may not necessarily reach the same ethical conclusions as opposed to healthcare professionals whose viewpoint is focused on broader organizational and community standards. Therefore, healthcare management students must learn to take into account the broader organizational and community standards as well.

Organizations must recognize that ethical decision-making contains personal bias. To achieve organizational excellence, effective and competent ethics resources must be available to all employees. As the healthcare environment evolves, healthcare organizations must consistently meet high professional and ethical standards. Aligning organizational culture and ethics standards does not occur simply because employees are part of an organization.

The healthcare field is a service industry that continues to attract diverse and highly trained professionals in both clinical and administrative roles. As a service industry whose core product is the patient and caregiver interaction, staff members are routinely confronted with dynamic situations that test their ability to respond appropriately to ethical issues (The Joint Commission, 2007). Healthcare regulations, standards, and scope of practice decisions should be universally taught, understood, and adhered to by caregivers at all levels in the organization (The Joint Commission, 2007).

Educational programs may provide the framework for addressing organizational ethics issues but training alone will not develop an organization culture that addresses and embraces ethical decision-making. Healthcare leaders must ensure that individuals with proven competencies to address ethics issues are readily available and that the organizational culture promotes ethical practices and ethical decision-making. Senior members of the organization are expected to take an active role in the development and demonstration of ethical decision-making.

Conclusion

Healthcare Professionals must constantly weigh moral, ethical, and regulatory factors in their decision-making (Purtillo, 2005). Ethical dilemmas are a constant challenge for healthcare managers, who must oftentimes act as mediators and disciplinarians when ethical judgment must be made. This study analyzed the process of decision-making involved in making ethical judgments.

It is the belief of the authors that healthcare professionals are altruistic by nature given that the healthcare service field is focused on providing care to others. It was anticipated by the authors that healthcare management students would have the ability to recognize and respond to ethical dilemmas. It was unknown which factors would weigh heaviest in their decision-making processes. The authors analyzed the students responses based on moral, ethical, and regulatory factors. Surveys indicated that, overall, students were able to recognize the ethical dilemmas in both cases.

Students most frequently based their decision-making on factors such as: health risks and benefits to patients, not disclosing information about medication safety and side effects, and ethical leadership. Students tended to weigh moral obligations more heavily than regulations and professional standards when making decisions. Students based their decisions not on professional standards or ethical codes of conduct, but reacted to what they perceived as the moral obligation. Overall, the decision making process was based upon the obligation to do what is best for the patient. The professional standards rarely (if at all) factored into the students' decision-making.

The authors hypothesize a correlation between the frequency of factors weighed in ethical decision-making processes and the attitudes of healthcare professionals. To determine if a correlation does exist, further surveys of current healthcare managers' decision-making in ethical dilemmas will be required.

It would be of interest to the authors to pursue further study of current healthcare administrators' perceptions and judgments of ethical dilemmas. This information would allow academicians to further the teaching of ethical analysis in healthcare. The intended goal of further studies would be to minimize any existing gaps between academic and professional knowledge and skills in the field.

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Appendix A

Questions:

1. Was there a breach of an ethical duty on the part of the nurse? If so, please provide a brief explanation.

   _____

   _____

2. Was there a breach of an ethical duty on the part of the manager? If so, please provide a brief explanation.

   _____

   _____

3. How would you have handled each of the ethical dilemmas you list above?

   _____

   _____

Circle your answer for the next four questions:

4. Was the nurse in compliance with the healthcare regulations and professional standards? YES or NO

5. Did the nurse have the authority to make her decision? YES or NO

6. Was the manger in compliance with the healthcare regulations and professional standards? YES or NO

7. Did the manager response appropriately when she fired the nurse? YES or NO

8. To resolve this dilemma, did you consider the following factors and if so, indicate their importance in your decision-making

Factors considered in decision making		Extremely Important 3	Somewhat Important 2	Less Important 1	Did Not Consider 0
For the children	Health risks for children				
	Ages of children				
	Missing school				
For the nurse	Scope of practice				
	Employment history				
	Termination of employment				
	Loss of wages/financial concerns				
	Autonomy in her position				
	Altruism—did she have a unselfish regard for the welfare of others				
For the manager	Responsibility to staff				
	Responsibility to patient				
	Personal integrity				
	Ethical leadership				
	Fairness—was her decision to terminate the nurse fair				
Total Points					

Appendix B

Questions:

1. Was there a breach of an ethical duty on the part of the psychiatrist? If so, please provide a brief explanation.

   _____

   _____

2. Was there a breach of an ethical duty on the part of the pharmaceutical representative? If so, please provide a brief explanation.

   _____

   _____

3. Was there a breach of an ethical duty on the part of the patient? If so, please provide a brief explanation.

   _____

   _____

4. How would you handle each of the ethical dilemmas you list above?

   _____

   _____

Circle your answer for the next four questions:

5. Was the psychiatrist in compliance with the healthcare regulations and professional standards? YES or NO

6. Did the psychiatrist have the authority to make her decision? YES or NO

7. Was the pharmaceutical representative in compliance with the healthcare regulations and professional standards? YES or NO

8. Did the pharmaceutical representative response appropriately when he provided the information about the drug to the psychiatrist? YES or NO

9. To resolve this dilemma, did you consider the following factors and if so, indicate their importance in your decision-making.

Factors considered in decision making		Extremely Important 3	Somewhat Important 2	Less Important 1	Did Not Consider 0
For the patient	Health risks for patient				
	Benefit(s) of drug for patient				
	Age of patient				
	Family of patient				
	Autonomy				
For the psychiatrist	Health risks for patient				
	Benefit(s) of drug for patient				
	Age of patient				
	Family of patient				
	Scope of practice				
	Other treatment alternatives				
	Autonomy in her position				
	Altruism—did she have a unselfish regard for the welfare of others				
For the representative	Responsibility to doctor				
	Responsibility to patient				
	Autonomy in his position				
	Personal integrity				
	Information he provided regarding side effects				
Total Points					

Enabling Humanities Encounters for People with Chronic Illnesses

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Abstract

Disease and illness are part of the human condition. Biomedicine focuses on disease; people experience illness. The Humanities have long chronicled and critiqued the human condition; therefore, the Humanities can be expected to offer insights to people with chronic illnesses. This paper elaborates how the Humanities can offer insights into the illness experiences relevant both to people with particular health problems and to the people within their intimate sphere. Many examples of particular works are provided from several Humanities genres, and a vision is presented of how encounters with Humanities could be facilitated for people who are interested in them. An exploratory survey briefly summarized suggests that most people with chronic illnesses are interested in gaining access to humanities works relevant to their health problems.

Keywords: Humanities, chronic illness, patients

Introduction

> In addition to medicine, other views must help the patient in challenging this existential impasse, helping him, first of all, to overcome that kind of separation of himself from his own body that illness normally produces; helping him in seeing illness as a manifestation of his *finitude*, without transforming it into an anguish, even when a total recovering of health is out of sight; helping him especially in giving some kind of positive sense to illness itself, bringing him to feel that illness does not strike the deepest levels of his personality, does not diminish his *dignity*. (Agazzi, 1998, p. 14)

Contemporary Biomedicine, with its primary focus on the pathological basis of health problems, has produced important gains in preventing and curing many deadly diseases. But these gains were not realized without losses—losses distinct from those attributable to iatrogenic illnesses. Lost in the progress of Biomedicine has been attention to the illness experience, or attention to those aspects of health problems that are not related to pathophysiology and treatment. The losses may derive from more than just shifting attentions, and could result from denial of the illness experience itself (Cassel, 1976).

That there is an illness experience apart from the direct results of disease processes, there can be no doubt. "Suffering and illness," Tymieniecka tells us, "are not incidental to an accident happening to the otherwise vital and prosperous course of an individual's life but are part and parcel of life, an inherent condition of its unfurling" (Tymieniecka, 1998, p. xviii). People with health problems wonder if their lives will be shortened or their life plans altered. They worry about being seen by family, friends, and colleagues as diminished and pathetic. They hope they can still contribute value to humanity, and they hope they can maintain their human dignity. People with health problems seek a new understanding of their place in the world, and they seek relief for physical symptoms and succor for mental anguish that medical treatments cannot provide (Brody 2003; Fife, 1994). The illness experience encompasses all these subjective perceptions associated with the consequences of health problems.

Yet, Biomedicine is not currently oriented philosophically or configured structurally to provide the relief people seek for their illnesses or the help they need to derive meaning from their illnesses. Perhaps Biomedicine should not be so orientated or configured. Given the ambitious and science-based agenda of Biomedicine, and Downie's assertion that "there can be tools other than scientific ones for dealing with the sickness, anxieties, and tears of human life," means other than those offered by Biomedicine should be pursued to address illness experiences (Downie, 1994, p. xi). The evolution of Biomedicine towards the scientific and away from the personal did not escape those who conceived the Medical Humanities as a "counterbalance to the relentless reductionism of the biomedical sciences" (Gordon, 2005, p. 5) by adding insights to Biomedicine from various humanities disciplines. Medical Humanities as a field, however, is most decidedly focused on physicians. As a result, the Medical Humanities address people with health problems only indirectly and only to the degree that physicians can and want to learn about the place of Humanities in illness and to use the Humanities in their care of people who are ill.

Thus there is a gap—a gap defining the needs that illnesses create for people whom Biomedicine does not address. The Humanities respond to these needs, in particular, when

they help people understand and accommodate the situations their health problems put them in; for example, adjusting to loss of control, revising life plans, finding meaning in an altered state, and overcoming the quotidian burdens illnesses impose. The Humanities can explain and illustrate how illness is part of the human condition, and that the journey through life can be encumbered by the effects of illness. The Humanities can show how such journeys so encumbered can be survived, because the arts, as the novelist Marcel Proust asserts, enable people "to travel not towards new landscapes, but with new eyes, to see the universe through the eyes of another, of a hundred others, to see the hundred universes that each of them can see, or can be" (Proust, 2003, p. 237). He surely meant to encompass what the arts can do to help people comprehend illness experiences, and he had his own illness history as a basis for his views (White, 1999).

A corpus of Humanities works relevant to people with chronic illnesses exists and people with chronic illnesses are interested in gaining access to this corpus, thereby validating a role for the Humanities in chronic illnesses. In this paper, *Humanities works* refers to literature, art, film, drama, music, and related disciplines, and *relevant to illness experiences* refers to interpretations of particular works that address illness experiences in meaningful ways. Throughout the paper frequent mention is made to directing people to the Humanities for *encounters* with potentially helpful works. The encounters envisioned are the interactions with particular works that help people derive interpretations useful for their personal situations, much like the encounter Arthur Frank sought after his heart attack, as he tells it, "because I did not have the resources I needed to generate a story about my life, as it had suddenly changed" (Frank, 2009, p. 186). Encounters with Humanities works are meant to be distinguishable in this paper from interventions with Humanities through creative art therapies (e.g., art or music therapy). Although creative arts therapies have been used effectively for decades, they tend to take the forms of clinical interventions and convey many of the essences and prejudices of Biomedicine, whereas encounters with Humanities reflect less structured and prescriptive interactions with particular works.

Humanities and Illness

Many people use the terms "disease," "illness," and "sickness" interchangeably, perhaps expectedly, given the way traditional sources define the conditions (Cassel, 1976; Boyd, 2000). These terms can be distinguished from one another, however, and distinguishing them is essential to understanding the value the Humanities offer people with chronic illnesses.

Disease, illness, and sickness can be distinguished by considering each as an independent entity with clear borders that exist in nature. Or, instead, they can be considered in a context that is derived mostly from how people think and talk about health problems, and how societies are set up to help people with health problems during a given era. When considered in this context, disease, illness, and sickness emerge as social constructs. The distinctions are useful in characterizing different aspects of the health problems that people face (Rosenberg, 2003; Kleinman, 1978). Writers, artists, filmmakers, and others who create works in the Humanities that are applicable to the illness experience understand and react to disease, illness, and sickness as they exist in a culture rather than as distinct entities in nature. Therefore, in this paper, illness is considered within a cultural context, because the picture of illness drawn from cultural analysis aligns better with Humanities content that addresses illness experiences.

Illness in Context

Although the distinctions among disease, illness, and sickness had been the subject of theoretical debate since the 1950s, Twadell (1994) and Marinker (1975) were among the first to attempt to make these distinctions relevant to contemporary health care in the 1970s. In general terms, these authors used straightforward definitions that linked disease to pathological elements of health problems, illness to subjective experiences of health problems, and sickness to social sanctioning of particular health problems. Kleinman (1988) also considers illness as the subjective experience of health problems, but he allows for the illness experience to extend to a circle of people around a particular person with health problems, such as family members, friends, and colleagues. (This group is characterized in this paper as the "intimate sphere.") He also extends the illness experience from what people feel in the way of symptoms to the practical consequences of such symptoms, such as missing work or school, and emotional responses such as anger and frustration.

Hofmann characterizes the distinctions among disease, illness, and sickness as a matter of perspective: specifically, disease represents a biological perspective, illness a phenomenological perspective, and sickness a behavioral perspective (Hofmann, 2002). These perspectives explain the different responses that health problems generate: the disease perspective motivates health care professionals and institutions to treat or cure health problems; the illness perspective causes people to recognize and respond to their health problems; and the sickness perspective results in societal decisions to assign the sick role status and corresponding rights and support for particular health problems.

While health problems can encompass all three of these perspectives, a particular health problem can be seen as illness alone, illness with sickness, illness with disease, sickness with disease, or illness with both sickness and disease. Fibromyalgia is an example of a health problem that produces illness and sickness; people who have it experience a specific set of symptoms and society has given it the status of sickness through payment for treatment and approval of drugs for it. However, a pathological basis for it remains elusive and so it is not consistently considered a disease. Migraine represents an example of illness with both sickness and disease because of the discernible symptoms that people conceive as illness, the pathological basis attributed to neurovascular mechanisms, and the societal recognition of it through payment for treatment and the approval of drugs for clinical management.

Referring to these perspectives can inform the selection of Humanities works to address particular situations. People with illnesses not associated with diseases or sicknesses, for example, may feel particularly isolated and disenfranchised; "they are adrift and they have to live with and make sense of their chaos" (Nettleton, 2004, p. 53). People in these situations are challenged to find meanings to their illness because there are no disease or sickness concepts they can use; how the illness progresses, for example, how the illness interferes with life in a serious way for a substantial period, or how the illness may diminish social status, position, and support. Various Humanities works could help such people see their illness as part of their humanity. That realization in turn could lead them to a more ordered understanding of their situation. People who have illnesses associated with disease or sickness may find it less challenging to understand their situation because Biomedicine or society has provided some level of explanation for it. Nonetheless, even when there is an associated disease or sickness, the illness experience is still often characterized by a feeling

of bewilderment and abandonment. People with illness and disease may feel aggrieved because their plight is neither recognized nor supported by society, while people with illness and sickness may feel legitimized but frustrated by the absence of a concrete biological explanation (and the haunting possibility that it's all in their heads). For these people, however, the associated disease or sickness concepts provide a foundation for the selection of Humanities content.

Segal puts a finer point on illness still by suggesting that it is a matter of argumentation: in other words, illness is what a person can persuade others to agree it is (Segal, 2007). People with migraine must persuade their physicians that they are not migraine-type people, but rather that they suffer from migraine symptoms. People with constellations of malaise, exhaustion, depression, and joint pain must persuade others that they suffer from fibromyalgia. Illness may thus be the outcome of negotiation (Rosenberg, 1992).

For all the theoretical constructs distinguishing the illness experience, Cassell may offer the most informative view with his prosaic explanation: "Let us use the word 'illness' to stand for what the patient feels when he goes to the doctor and 'disease' for what he has on the way home from the doctor's office" (Cassell, 1976, p. 48). Karr's explanation, through a character in a play she wrote, is even more prosaic: "The illness equals the disease plus the person" (Karr, 2000, p. 192). Thus, to select Humanities content that corresponds to particular illness experiences in a meaningful way, a conceptual basis for illness experiences is needed to guide our selections.

Illness in Humanities

Scholars and clinicians are not alone in attempting to distinguish among disease, illness, and sickness, or at least in attempting to describe the illness experience. They are joined by writers, artists, filmmakers, and the like who also create Humanities works. Many who have considered the illness experience see its primary effect as isolating. For people who are ill, Virginia Woolf wrote, "the world has changed its shape...the whole landscape of life lies remote and fair, like the shore seen from a ship far out at sea" (Woolf, 2002, p. 8). Worse, they "cease to be soldiers in the army of the upright; [they] become deserters" (Woolf, 2002, p. 12). To Susan Sontag, "Illness is the night-side of life, a more onerous citizenship" (Sontag, 1990, p. 3). Whereas Woolf and Sontag wrote of illness as another place metaphorically, Thomas Mann described the other place literally through a character in *The Magic Mountain* (Mann, 1996), who tells of having to live "up here" in a sanitarium high in the mountains of Switzerland for treatment of tuberculosis, whereas those who do not need treatment for tuberculosis live "down below".

These writers see the illness experience as something larger than biology. Disease and sickness are confined mainly to biological boundaries, whereas illness as a human experience is not. Thus writers, artists, filmmakers and their kind have much more room to explore it (Franzen, 2003; Frank, 1997). What narratives, for example, can be generated by the blood vessels that expand to cause migraine headaches at the command of the neurotransmitter serotonin—the biology of migraine? Yet the migraine experience produces narratives that extend beyond its biology. Siri Hustvedt juxtaposes biomedical and literary narratives of migraine in her novel *The Blindfold* (Hustvedt, 1992) through the description of a migraine episode a character gives her doctor, followed by his response:

"But as soon as I stepped inside my apartment, I felt a tug on my left arm, just as if someone had yanked it hard. I lost my balance and fell down. I was so dizzy and sick to my stomach that I didn't get up for a long time. While I was sitting there on the floor, I saw lights, hundreds of bright sparks that filled up half the room, and after they disappeared, I saw a big, ragged hole in the wall. That hole scared me to death, and the strange thing was that I didn't experience it as a problem with my vision. I really thought that part of the wall was missing. I don't know how long it lasted, but after the hole was gone, the pain started." Dr. Fish picked up the microphone. "The patient suffered a scintillating and a negative scotoma." (p. 93)

Similar juxtapositions showing how the illness experience extends beyond biology in Humanities works can be derived from biomedical texts and literary or artistic works. Compare how a widely read medical text describes clinical manifestations of the middle stage of Alzheimer's disease with a fictional character's description of the same experience in a recently published novel. The medical text describes the middle stages of Alzheimer's disease as,

Language becomes impaired—first naming, then comprehension, and finally fluency. In some patients, *aphasia* is an early and prominent feature. Word finding difficulties and circumlocution may be a problem even when formal testing demonstrates intact naming and fluency. *Apraxia* emerges, and patients have trouble performing sequential motor tasks. Visuospatial deficits begin to interfere with dressing, eating, solving simple puzzles, and copying geometric figures. Patients be unable to do simple calculations or tell time. (Bird & Miller, 2011)

Walter Mosley, in his novel, *The Last Days of Ptolemy Grey* (Mosley, 2010), provides a literary description of middle-stage Alzheimer's disease through the experience he develops for Ptolemy,

That's how Ptolemy imagined the disposition of his memories, his thoughts: they were still his, still in the range of his thinking, but they were, many and most of them, locked on the other side of a closed door that he'd lost the key for. So his memory became like secrets held away from his own mind. But these secrets were noisy things; they babbled and muttered behind the door, and so if he listened closely he might catch a snatch of something he once knew well. (p. 12)

The Humanities can expand on the biological descriptions of diseases by creating narratives of illness experiences as lived experiences, with place, time, and other elements of our lives accounted for. By encountering the range of narratives and genres available to the Humanities, people with health problems—as Proust anticipated—will be able to see through the eyes of many others the many different ways they can comprehend their lives and attach meaning to them.

Articles

Linking Humanities to Illness Experiences

Eighty years ago, Virginia Woolf famously lamented that "illness has not taken its place with love and battle and jealousy among the prime themes in literature" (Woolf, 2002, pp. 3–4), perhaps because when it comes to describing illness, "there is a poverty of language" (Woolf, 2002, p. 6). She further thought the public would savage any literature featuring influenza as a plot line. But, even before her lament some noted authors had featured influenza—the calamitous influenza pandemic of 1918—in their fiction (Belling, 2009). As modern medicine has discovered more diseases and invented more treatments, and as Western industrialized nations have categorized more of life's troubles and challenges as health problems, nearly everyone now in Western societies could be said to be in the midst of an illness experience, directly or indirectly. Therefore what can be expected, and perhaps is now happening, are more Humanities works in all genres featuring illness in ways that provide useful insights.

Humanities and Individual Illness Experiences

People who are most likely to benefit from encounters with Humanities works relevant to their illness experiences are those whose lives are significantly affected by the intensity and constancy their health problems impose. The illness experience for these people is "like the volcano: it does not go away. It menaces. It erupts. It is out of control. One damned thing follows another" (Kleinman, 1988, p. 44). Thus, sorting out one's own illness experience is made particularly difficult by associated symptoms, disabilities, fears, threats, and burdens. The Humanities offer perspectives not so encumbered and thereby give people views of their situations that they themselves cannot generate. Skilled writers, for example, "help us to see the world and our own place within it in a new light—a light that falls from a slightly different direction revealing subtly different detail" (Heath, 2005, p. iv).

Consider epilepsy. Seizures are chaotic; they are caused by chaotic nerve dysfunction, they generate chaotic body movements, and they produce chaotic lives. Epilepsy figures heavily in the trajectory of the main character of Paul Harding's novel *Tinkers* (Harding, 2009). In telling the story of Howard, Harding vividly describes seizure events through metaphors of lightning and electrocution.

> The aura, the sparkle and tingle of an oncoming fit, was not the lightning—it was the cooked air that the lightning pushed in front of itself. The actual seizure was when the bolt touched flesh, and in an instant so atomic, so nearly immaterial, nearly incorporeal, that there was almost no before and after, no cause A that led to effect B, but instead simply A, simply B, with no *then* in between, and Howard became pure, unconscious energy. It was like the opposite of death, or a bit of the same thing death was, but from a different direction: Instead of being emptied or extinguished to the point of unselfness, Howard was over-filled, overwhelmed to the same state. If death was to fall below some human boundary, so his seizures were to be rocketed beyond it. (pp. 47–48)

Harding offers people with epilepsy a way of conceptualizing their experience, and also a way to explain the seizure experience to themselves and others. By embedding the

illness experience in stories, Harding may enable people with epilepsy to place their own experiences in their lives in ways that can reduce chaos, uncertainty, and threats (Frank, 2009). Through an imagined character in the first part of his poem, Diabetes (Dickey, 2001), James Dickey reflects on the experience of discovering and coming to grips with a diagnosis of diabetes mellitus:

> One night I thirsted like a prince
> Then like a king
> Then like an empire like a world
> On fire. I rose and flowed away and fell
> Once more to sleep. In an hour I was back
> In the Kingdom staggering, my belly going round with self-
> Made night-water, wondering what
> The hell. Months of having a tongue
> Of flame convinced me: I had better not go
> On this way. The doctor was young
>
> And nice. He said, I must tell you,
> My friend, that it is needles moderation
> And exercise. You don't want to look forward
> To gangrene and kidney
> Failure boils blindness infection skin trouble falling
> Teeth coma and death. (p. 199)

The Humanities offer people ways to organize and comprehend their illness experiences. But people also seek ways for others around them to comprehend their experiences, because they intuitively sense what Elaine Scarry (1985) describes: "to have great pain is to have certainty; to hear that another person has pain is to have doubt" (p. 4). Therefore, being able to articulate their experiences becomes necessary if they are effectively to help others, including family, friends, and colleagues, get closer to comprehending illness experiences that even those in the intimate sphere cannot otherwise fully appreciate. The Humanities fill this need by providing a vocabulary and narrative for describing the illness experience to others.

The Humanities can also expand on individual illness experiences. Kleinman (Kleinman, 1988) emphasizes that certain illness experiences go beyond the individual to reflect social problems within populations. As an example, he describes how society recognizes tuberculosis as a health problem for individual members, but also as an indicator of poverty and malnutrition among certain groups. Humanities can effectively elaborate the broader implications of illness conditions such as tuberculosis. Alice Neel this captures this very scenario in her painting *T.B. Harlem*, where she shows her lover's brother recovering from a surgical procedure to collapse a lung as treatment for tuberculosis (Figure 1). The painting details the physical effects of rib removal, but it also conveys a sense of resignation and helplessness that attends poverty and social conditions predisposing to tuberculosis. Neel knew these conditions and their consequences from having taken up residence in Harlem in 1938 and closely observing and recording daily life there for the next 24 years (Barclay, 2005; Hoban, 2010).

Figure 1. *T.B. Harlem* (Alice Neel, 1940) © The Estate of Alice Neel. Courtesy David Zwirner, New York. Oil on canvas, 30 × 30 in., National Museum of Women in the Arts, Washington, D.C. Gift of Wallace and Wilhelmina Holladay.

The modern-day illness experience encompasses interactions with health care systems: interactions, indeed, that have important influences on what illness experiences become. Various Humanities genres have begun to focus on these interactions and their impacts. Margaret Edson's play *Wit* (1999), for example, imagines what happens when people with terminal diseases agree to try brutal experimental therapies—what happens when they transition from being patients under the care of health professionals to becoming experimental subjects of scientific researchers. Mosley's novel, *The Last Days of Ptolemy Grey* (Mosley, 2010), in addition to providing perspectives on what a person with dementia may experience, it also provides an opportunity to imagine making a choice between continuing to live indefinitely in a fairly advanced stage of dementia or taking a drug that would restore mental acuity for just a few weeks with the trade-off of an earlier death. Representations such as these slow down the action and play out the consequences of different choices, thereby allowing a range of ways for people to reflect on their own past decisions or better prepare for such decisions when they must be made.

Humanities and Illness Experiences in the Intimate Sphere

Illness experiences are not confined to the people who have the associated disease or condition. Family members, friends, and colleagues, among other intimates, may share in a person's illness experience. However, the illness experience of intimates takes other forms and is often derived from their interactions with the person who has the health problem. The Humanities do not neglect the impact of health problems on intimate spheres.

Drama can effectively show the illness experience within a group of intimates through the interactions characteristic of the genre. The recent, Pulitzer prize-winning musical, Next to Normal (Kitt & Yorkey, 2009) brings to life the collective illness experience through interactions among intimates. This work brings into full display the pain, emotion, disorientation, and suffering experienced not only by a family member with mental illness, but by the other family members as well, as is evident through their interactions. In particular, through successive songs, Diana—the mother in the family and the member who is mentally ill—tries to explain to her husband, Dan, what she is going through:

> *Diana:*
> The sensation that you're
> screaming
> But you never make a sound,
> Or the feeling that you're falling
> But you never hit the ground—
> It just keeps on rushing at you
> Day by day by day by day...
> You don't know
> You don't know what it's like
> to live that way.

Dan's response makes clear that he, too, is suffering and that some of his suffering comes from not being able to comprehend Diana's experience or knowing how to respond to it:

> *Dan:*
> Are you bleeding?
> are you bruised,
> Are you broken?
> And does it help you to know
> That so am I?
>
> Tell me what to do
> Tell me who to be
> Look at me
> So I can see what you see

Featuring blaring, electric guitars and a driving rock beat, the musical score conveys the urgency of this particular exchange.

Next to Normal shows how the Humanities can imagine ways in which the illness experience permeates through intimate spheres. The Humanities can also draw attention to the important—not to say gut-wrenching—predicaments into which illnesses force intimates. In so doing, the Humanities provide a means to anticipate and possibly solve problems outside the interest and wherewithal of Biomedicine. Take, for example, the common scenario families face in decisions to press on with last-resort therapies. Typically, clinicians discuss the medical dimensions of such decisions with patients and their families, but they stop short of discussing the other important dimensions, such as whether the costs or personal sacrifices entailed in last-resort therapies are justifiable to all the intimates. Perhaps it is expecting too much from clinicians, however, if they are asked to provide guidance on these more personal dimensions of such decisions. Further working against these discussions are political discourses around health care reform that label clinicians (or anyone else) involved in them "death panel" advocates.

Yet the Humanities offer media through which family members may rehearse conversations with clinicians about decisions to do with last-resort therapies based on personal situations, including the impact of costs. Lionel Shriver's recent novel, So Much For That (Shriver, 2010), is a particularly good example. The novel tells the story of Glynis Knacker from when she is diagnosed with mesothelioma, around the time her husband Shep is about take them into his long-dreamed-of retirement on a tropical island. Shriver focuses attention on the cost impacts of health care throughout the story, but never more closely than in a conversation Shep has with his wife's physician, Dr Goldman. The doctor proposes an experimental therapy costing around one hundred thousand dollars, a therapy that has little chance of changing Glynis's prognosis, which is three weeks to live.

"A hundred grand. There's 'not much to lose'? I guess I'm not in your income bracket. Since that strikes me as a whole lot."

"...We're talking about your wife's life here...I have to assume that money is a secondary issue at best, if it's an issue at all."

"So, if I say it's an issue, I'm an animal, right? But even if I fall in line and say, by all means, doctor, do anything you can...because I love my wife and *money is no object*. Why do you assume I've got a hundred grand?"

"...It's really Mrs. Knacker's decision, when she wants to call off further treatments...she sounded keen to try it."

"...I realize she'll try anything. But it is not my wife's decision if she's not the one who's going to pay for it."

Goldman was overtly discomfited by this kind of talk. He kept averting his gaze, working his face without concealing his disapproval, and edgily hitting his keyboard's space bar. "I want to be very clear, Mr. Knacker. This drug is our last hope." (pp. 378–379)

Encountering this exchange lets readers imagine how the conversation about last-resort therapies can be extended from clinical considerations alone to important and difficult personal considerations. Conversations of this nature are not commonly conducted in clinical

settings; not many clinicians are comfortable with having them nor are they often trained to conduct them. Also, at least at the present time, societal support of such conversations is subject to heated political debate that has effectively halted any progress towards systematic integration into health care interactions. Thus, the Humanities may be the only media in which any social learning can occur. Given the ability of writers, artists, filmmakers and the like to describe such interactions, insights into these conversations and training for them are best placed in the various Humanities genres.

Lisa Genova, in her novel *Still Alice*, includes encounters that shed light on many of the difficult decisions confronting intimates of people with Alzheimer's disease. A decision she imagines in this novel involves an exciting and seemingly irresistible career opportunity that comes to Alice's husband. Alice, herself, has early-onset Alzheimer's disease, and at the time the opportunity presents itself, she is at an advanced stage and is easily and frequently disoriented to time and place. Her husband's career opportunity requires that he move from their very familiar Boston environs to New York City. Genova sets up a debate among Alice's husband and his two daughters, who press him to let Alice participate in the decision when he says Alice can't know what she wants ("It's like you don't get that she's not gone yet"), to open his heart when he says he's just trying to make a rational decision ("What's wrong with being emotional about this?"; "Why isn't the emotional decision the right decision?"), to consider practical consequences ("Dad, how on earth do you think you can go to New York and do this without our help?"), and question the effectiveness of his caretaking plans ("I don't want strangers taking care of her. They're not going to hug her and love her like we do.") (Genova, 2009, p. 261).

The scenario Genova imagines for the family in *Still Alice* is common to the course of many health problems. Working through these situations in novels, for example, can give readers a general sense of how events may unfold and how they might even be shaped. These depictions can help provide a vocabulary for the conversations to work through these scenarios within intimate spheres.

Conjuring complex interactions and scenarios is not the only way the Humanities depict the illness experience of intimates. Worry and fear, for example, are very common and straightforward experiences for those close to a person with serious health problems, and are dealt with in the Humanities. The painter Edvard Munch put a particular focus on poor health and its consequences, as he himself was deeply familiar with both: "Illness, insanity and death were the black angels that hovered over my cradle" (Prideaux, 2005, p. 37). He was profoundly affected by the deaths of his mother when he was 6 years old and his sister when she was 15 years old and he was just a year younger, both having succumbed to tuberculosis. Many of his paintings show the impact of illness and death on family and friends. Munch's rendering of his distraught aunt at the bedside of his sister who is bedridden with tuberculosis in The Sick Child shows the profound effect of illness on a family member (Figure 2).

While our current time rejects death as a part of the natural history of many diseases, it also rejects grief as an appropriate response to death of an intimate, or as a condition worthy of its own course (Lane, 2007; Horwitz & Wakefield, 2007). Works by Munch and other artists show the natural convergence of grief with illness and death.

Figure 2. The Sick Child (Edvard Munch, 1907) ©Tate, London 2012.

Humanities Encounters for People with Chronic Illnesses

If a sufficient corpus of relevant Humanities works exists, is there a workable mechanism by which people with chronic illnesses interested in encounters with these works can get access to them? Indeed, there is no purpose-built mechanism currently in existence to connect people with particular chronic illnesses to relevant Humanities works. Such a vision is needed to motivate and guide development of content, storage media, and delivery channels. A workable vision could be created from elements of programming available now in different places and forms.

A vision for facilitating Humanities encounters is likely to involve a centralized source of works relevant to a wide range of illness experiences. The Medical Humanities academic community has assembled databases of Humanities content, but mostly to

serve professional and medical education and training. A particularly robust database of Humanities content related to health care is the Literature, Arts, and Medicine Database at New York University (www.litmed.med.nyu.edu). This database could serve as a model or even be adapted to serve the interests of people with chronic illnesses if the Medical Humanities community included content directly relevant to this population, and not just for health care professionals.

A vision featuring a centralized content source will need specific elements both to draw people to the database and to distribute the content to interested audiences. These elements could be the preserve of the various groups with interests in the Humanities and patient advocacy. For example, the Medical Humanities community could facilitate encounters with the database in teaching health care professionals the value the Humanities bring to people with chronic illnesses. For students and clinicians, Medical Humanities thought-leaders could identify works for health care professionals to recommend to their patients for specific circumstances. They could encourage health care professionals to direct their patients to the database. Professionals in the creative arts therapies could draw on the database for therapeutic purposes and could direct patients to it for their own explorations. Patient advocacy groups could mine the database for content relevant to their constituencies and provide content directly, as well as show patients how to access the database for their own interest. Professional specialty organizations such as the American Diabetes Association or the American Cancer Society could have an interest in using content from the database and in directing their constituencies to it. Indeed, the American Society of Bioethics and Humanities is likely to have a high degree of interest in facilitating access to the database for its constituency, if not in driving the entire project. The vision developed around the database could also incorporate health care purchasers, such as health insurance carriers and managed care organizations. These organizations continually seek ways to help plan members manage their illness experiences.

A coherent vision for a systematic arrangement to provide access to Humanities works that speak to the particular situations of people with chronic illnesses thus centers on a database with links to a range of constituencies who have a common interest in facilitating such encounters. The database anchors the vision, and management of the entire arrangement is tied to the database. A number of business arrangements could support this vision. A combination of philanthropy and commercialization opportunities operating in an academic center might be particularly well suited for the enterprise.

People with chronic illnesses have shown an interest in encountering relevant Humanities content. In an exploratory, Internet-based survey of a pre-established panel of 1,000 people with a wide range of chronic illnesses, more them 60% of them indicated an interest in "movies, literature, art, history, or music" related to their particular illness experiences (Teagarden, 2009). Indeed, about one-quarter of the respondents reported that they have experienced benefits from the Humanities in the past. A high percentage of respondents interested in these encounters reported that they would make use of access methods involving a database they could browse, search, or receive alerts from. Several health plan managers who were surveyed separately indicated that they would be interested in facilitating access to Humanities content for their members with chronic illnesses. Thus, it may be that if a way for people with chronic illness to encounter the Humanities were built, many would come.

Conclusion

> As *Homo aestheticus*, we really require beauty and meaning—those answers to human questions and desires that are to be found in (what should be evident in the name we give them) "the humanities" (Dissanyake, 1992, p. 3).

Illness is part of the human condition. Indeed, illness is becoming a bigger part of the human condition as more diseases and treatments are discovered and as more of life's challenges are classified as health problems that generate corresponding illness experiences. And yet, as illness experiences broaden in scope and constitute more and more of the human condition, Biomedicine is narrowing its scope to the science of disease as it is concerned with smaller and smaller units of the human, down to the fundamental units made up of base pairs. While more of the pathological aspects of health problems can be explained and managed, the illness experience of health problems remain largely unattended. The Humanities, however, already address illness experiences outside the scope of Biomedicine and could increasingly provide a context to help those with chronic illnesses understand and explain their predicaments.

The illness experience is becoming a more common focus of many Humanities works. Humanities works relevant to specific illness experiences can be found in many genres, and an increasing interest in the illness experience as manifested in the Humanities is easily discernable. A search of only very modest intensity will turn up poetic descriptions of life with new-onset diabetes, literary treatments of the frights self awareness of dementia cause, dramatic depictions of the impact psychotic breaks can have on families, paintings that render the abject misery illness can impose, and stories that feature real and difficult decisions people are often forced to make because of illness. The availability of seemingly relevant works will be of little consequence, however, without a corresponding interest among people with chronic illnesses. The information about whether such an interest exists, while isolated and sparse at present, is encouraging.

This proposition anticipates the availability of coordinated systems to develop, store, and distribute Humanities content to people with chronic illnesses. The architecture of a potentially effective arrangement can be constructed from existing institutions and configurations among academic centers, professional organizations, patient advocacy groups, and health care purchasers. Such an approach lends itself to support by a combination of philanthropy and commercialization opportunities. The arrangement that ultimately works will be based on the understanding that illness experiences are important and that the Humanities bring succor and meaning that Biomedicine does not.

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Exploring the Relationship between Human Variation and Dengue Outcome within the Context of the Tuskegee Syphilis Study

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Abstract

This article explores how an analysis of the Tuskegee Syphilis Study and the context in which it developed and was initiated can provide an important lesson to current researchers investigating the relationship between human variation and disease outcome. The specific disease focused on is dengue fever, one of the most important mosquito transmitted disease in the world and a major cause of disease and death in the tropics. There is currently a hypothesis that, in comparison to other populations, individuals of African descent living in tropical regions of the Americas tend to be asymptomatic or display mild/moderate symptoms of dengue. Drawing on the Tuskegee Syphilis Study as a reference, this article discourages racial explanations of disease etiology and discusses the importance of integrative analyses that situate the individual, community and population within local historically relevant cultural and environmental contexts.

Keywords: Racial Medicine, Human Variation, Dengue

Introduction

The Tuskegee Syphilis Study was a forty-year (1932–1972) clinical investigation initiated by the United States Public Health Service in Tuskegee, Alabama. While the study's stated aim was to investigate the natural progression of untreated syphilis in poor African American men, there were two implicit assumptions underlying the study's development and initiation. These assumptions included: (1) the theory that African Americans were biologically distinct from European Americans; and (2) the idea that racial difference resulted in African Americans being inherently inferior to European Americans. Investigation of the natural progression of untreated syphilis in poor African American men would compile scientific data on the manifestations of this difference (as it related to syphilis) and this evidence would document their inherent inferiority (Jones, 1991).

This article explores how an analysis of the Tuskegee Syphilis Study can provide an important lesson to current researchers investigating the ethnic correlates of dengue, one of the most important mosquito transmitted diseases in the world and a major cause of morbidity and mortality in the tropics. There is currently a hypothesis postulating that in comparison to other populations, individuals of African descent living in tropical regions of the Americas tend to be asymptomatic or display mild/moderate symptoms of dengue (Guzman et al., 1990; Halstead et al., 2001; Brown et al., 2004; Seirra, Kouri and Guzman, 2007; Blanton et al., 2008). Is this health disparity racial? Can race be used as a variable when predicting the severity of dengue infection?

The main assumption underlying the Tuskegee study was that phenotypic measures of race accurately describe human genotypic variation and these phenotypic characteristics can predict health outcome. Using the Tuskegee study as a framework, current dengue researchers should begin asking themselves if 18th century racial constructs can truly depict human variation. Given the current information regarding genetic variability, is it possible that human variation is more complex and may be investigated beneath a racial level? Can further investigation beneath a racial level allow for a more accurate prediction of health and disease?

In the forty-year aftermath of the Tuskegee Syphilis Study, race has continuously been critiqued as an inadequate variable when used as a principle component in the determination of disease outcome (Jones, 1991). Nevertheless, the claim that race is an important variable in clinical practice, public health and biomedical research, continues. By analyzing the dialogue surrounding the ethnic correlates of dengue with the framework of the Tuskegee Syphilis Study, this article discourages simplistic explanations of disease etiology and discusses the importance of integrative analyses that situate the individual, community and population within local historically relevant cultural and environmental contexts.

Late 19th/Early 20th Century Racial Science and Medicine

While The Tuskegee Syphilis study began in 1932, the assumptions underlying its scientific premises can be traced to 19th and early 20th century racial science and medicine. Racial science and it application (medicine) claimed that races differed in obvious observable features, such as skin color and body proportions and that these observable features could be used to predict characteristics such as intellect, morality, character, disease predisposition and resistance (Graves & Rose, 2006). Racial differences were defined as resulting from evolution and adaptation in ancestral continental origins.

An analysis of the history of medicine in the Americas reveals that during the 19th century, racial medicine often served to justify the enslavement of African Americans (Peard, 2000; Savitt, 2002). According to W. Michael Byrd and Linda A Clayton:

> By the 19th century, racially oriented European pseudoscientific data, along with that produced by the American School of anthropology, was being used in the U.S. to justify and defend black slavery. Because of the increasing cultural authority granted America's scientific and medical communities, the nation's worship of the new science buttressed America's commonly held racial mythology…By the late19th and early 20th centuries, American medical journals and textbooks were laced with

pseudoscientific racist principles, derogatory racial character references, and pronouncements of impending black racial extinction (Byrd & Clayton, 2001: 185–6).

In the 1915 article entitled "Remarks on the Health of Colored People" published in the *Journal of the National Medical Association*, J Madison Taylor stated that "races of people who have lived for thousands of years in certain climates become adapted in their makeup to survive and flourish under similar conditions…" and would "inevitably suffer if suddenly removed to other climates or environments whole different, and for which their structure, skin, color, nostrils and the like have become entirely un-adapted (Taylor 1915: 74–75)." African American populations were characterized as particularly mal-adapted to American society since they evolved in Africa. Taylor continues by stating that African Americans originated in the "the lowlands of Equatorial Africa"….and "cannot possibly be expected to do well in a country where it freezes hard during winter (Taylor, 1915: 76)." In the 1903 article entitled "Tuberculosis in the Negro," published in the *Journal of the American Medical Association*, Seale Harris stated that in contrast to African Americans "the whites have many centuries of enlightenment and civilization under such varied conditions that there has been the psychical and physical development, which fits him to endure the manifold dangers of disease which beset us in our struggle for existence in this complex age… (Harris, 1903: 836)."

High morbidity and mortality from tuberculosis and syphilis were often used as proof of the inability of African Americans to adapt to the American environment (Hoffman, 1896; Gamble, 1989). According to Frederick Hoffman:

> The vitality of the Negro may well be considered the most important phase of the so-called race problem, for it is a fact, which can and will be demonstrated by indisputable evidence, that all the races for which statistics are obtainable…the Negro shows the least power of resistance in the struggle for life (Hoffman, 1896: 37).

An analysis of the literature from the early 20th century reveals that health outcome (high morbidity and mortality) was thought to result from biological inferiorities that left African Americans susceptible to disease. In 1903 Seale Harris describes research examining some of the biological differences between African and European Americans. He cites the work of M.L. Perry, pathologist of the State Sanitarium of Georgia who found that "the average weight of the brain of the Negro was 100 grams …less that that of the whites." Harris explains "it is also well known that in the brain of the Negro the convolutions are less complex, and the sulci are shallower than that of the Caucasian….Thus the Negro's brain is nearer to the Simian type (Harris, 1903: 835)." Harris also cites research conducted on US soldiers where among African Americans "the chest measurements were full, but their lungs were always lighter and smaller than those contained in the same sized chest among white troops (Harris, 1903: 835)." He concludes by asserting "all observers agree that there is less development of the lungs of the Negro than for the whites and this physiological difference no doubt accounts for…the inordinate mortality from …pulmonary diseases (Harris, 1903: 835)."

In addition to pulmonary disease, African Americans were also portrayed as being more susceptible to syphilis. In a 1915 article entitled "The Negro as a Problem in Public

Health Charity" published in the *American Journal of Public Health*. Lawrence Lee stated "as a city physician during three years I treated 1,426 negroes, 480 of whom had syphilis in some evident form." It was Lee's personal belief that "more than 50 percent of the colored race suffered with this disease, either inherited or acquired. If this is the case….syphilis is almost the important factor in the high death rate of the negro race (Lee, 1915: 207)." Contamination with syphilis was described to result from an immoral lifestyle (Brandt, 1978). In the 1908 article "Tuberculosis among the Negroes" published in the *Journal of the Southern Medical Association* W.J. Northern described how during the early 20th century syphilis was "traceable to enfeebled constitutions broken down by gross immoralities" with "the masses of negro people thoroughly de-battered through moral decay, and their physical degeneracy is making a very hot-bed for all infectious and contagious diseases (Northern, 1908: 413)."

The above discussion illustrates that the belief that race could be used to predict disease outcome was accepted as legitimate reasoning within scientific and medical communities. This theory and practice of racial science reached its fruition in the Tuskegee Syphilis Study carried out by the United States Public Health Service between 1932–1972. The study sought to observe the pathogenesis of untreated syphilis among a sample of African American men. The concern with understanding the pathogenesis among African American men originated from 19th century racial scientific theories that there was significant biological variation among racial groups (Jones, 1991). At the beginning of the 20th century, this type of thinking became embedded within the larger eugenics movement that reinforced and updated the "racial medicine" of the 19th century, establishing it on firmly modern, scientific grounds.

PHS Surgeon General Hugh Cumming initiated the Tuskegee study, and assistant surgeons general Taliaferro Clark and Raymond A. Vonderlehr presided over the study during its first decade. All three individuals were educated and trained during a period when eugenics ideology was prominent in American thought. As a result of this ideological influence, the study inadvertently supported misguided beliefs that biological differences distinguished African and European Americans from each other and that racial groups had differing resistances and susceptibilities to disease (Lombardo & Dorr, 2006). Thus, a scientific study such as Tuskegee that planned to investigate the pathological course of syphilis among African American men would in effect provide scientific data correlating racial differences to disease course. Consequently, while the Tuskegee Syphilis Study was an examination of untreated syphilis, it could potentially provide scientifically collected data demonstrating the supposed racial characteristics of syphilis that were long considered evidence of inherent African American difference and inferiority (Brandt, 1978; Crenner, 2011).

Thus, the Tuskegee Syphilis Study was the culmination and application of racial science in medicine. Racial theory postulated that there were real differences between racial groups and the observed high morbidity and mortality among African American populations from diseases like tuberculosis and syphilis provided proof that the race was inferior and unfit for survival in the American environment. However, it is important to note that there may have been problems with the collected and compiled data. According to Venessa Gamble difficulties with diagnosis and the reporting of disease make the accuracy of some historical health data questionable (Gamble, 1989). For example, in a study investigating the changing conceptions of disease on the reporting of deaths from 1859–1912 in Massachusetts,

Anderton and Hautaniemi-Leonard (2004) found that reported cause of death reflect and are limited by the historical context in which they were recorded. Making special reference to tuberculosis they state that lower social class and standing was often attributed as contributing to death from tuberculosis. They suggest that this may contribute to the high number of deaths listed as tuberculosis among young and working age men who lived in three lower class towns in Massachusetts. Thus, recording the cause of death as tuberculosis may reflect the belief that lower social class people were more prone to the disease rather than to the actual state of affairs (Anderton & Hautaniemi-Leonard, 2004). In the racialized climate of the late 19th early 20th century United States, it is possible that this context may have resulted in many misdiagnoses among African Americans, artificially inflating numbers as they related to morbidity and mortality. In regard to syphilis:

> Part of the justification for the Tuskegee Study was the finding in 1930 in Macon County (where Tuskegee is the county seat) of a prevalence rate for syphilis of an astounding 39.5%. But the same prevalence survey of African Americans in five other counties also found a figure as low as 8.9%, less than "in many white groups" as Surgeon General Thomas Parran wrote, which raised questions about the assumption that African Americans were, as one physician noted, a "syphilis-soaked race." Two years later, in the original data for what became the Tuskegee Study and in a different part of Macon County and only with men over 18 with presumed late latent disease, the positives had dropped to 22.5% (Reverby, 2008: 481)

It is possible that the radicalized context in which Tuskegee developed resulted in researchers unconsciously exaggerating the morbidity and mortality of African Americans, ultimately searching and finding what they were looking for. Questions were formulated in such a way that any legitimate answer could only validate a social preference (see Gould, 1981).

19th and early 20th century racial science that hierarchically ranked racial groups in terms of evolutionary superiority and inferiority is not likely to be replicated in current studies attempting to correlate human variation with health outcome. What is in danger of being replicated is the idea that human variation can be defined using traditional racial categories. If race continues to be used, then the danger still exists that racial disparities will be documented and perhaps exaggerated to the detriment of exposing the actual causes of disease outcome. The remainder of this article discusses how the use of race may result in oversimplified analyses that neglect the complexity of disease outcome.

Dengue and Race

The idea that race can assist when predicting health outcome currently continues and can be observed in the hypothesis that African descendent populations are resistant to severe dengue infection. Dengue belongs to the family *Flaviviridae* genus *flavivirus*. There are four dengue serotypes including DEN 1, DEN 2, DEN3, and DEN 4 and the most common vector for dengue virus is the *Aedes aegypti* mosquito (World Health Organization, 2002). Dengue infection generates a broad spectrum of clinical illness ranging from asymptomatic infections, mild dengue fever (DF), to severe and life threatening hemorrhagic disease including dengue hemorrhagic fever (DHF) and dengue shock syndrome (DSS). DHF/DSS is characterized by high fever, increased vascular permeability,

bleeding, liver enlargement, circulatory failure and accompanied by thrombocytopenia and hemoconcentration.

Currently, the data supporting some form of biological or inherent resistance to dengue among African descended populations are compelling. There are data from the Caribbean and Latin America that populations of African descent tend to be asymptomatic or display mild/moderate symptoms (Guzman et al., 1990; Halstead et al.., 2001; Brown et al., 2004; Seirra et al., 2007; Blanton et al., 2008). In a retrospective study of the 1996 DEN1 epidemic in Trinidad, the pattern of dengue did not correspond with demographic patterns in the country. In Trinidad the population is composed of South Asian descended populations (40.3%), African descended populations (39.6%), populations of mixed ancestry (18.4%) and other ethnicities (1.6%). There was an overrepresentation of South Asians (50%) experiencing dengue and fewer persons of African origin (35%) and of mixed race (11%). Teelucksingh and colleagues (1997) had previously reported a higher incidence of more severe dengue infection and mortality in South Asian people (colloquially referred to as East Indians) in Trinidad (Teekucksingh et al., 1997; Brown et al., 2004). A study conducted in Haiti revealed that dengue plaque reduction neutralization test (PRNT) antibodies were highly prevalent among Haitian children. However, communication with three pediatricians in Port-au-Prince confirmed that there was an absence of children hospitalized or dying with the clinical course, symptoms, or signs suggestive of DHS/DSS. Using a mathematical model it was estimated that the average infection rate in Port-au-Prince is about 30% and thousands of cases and hundreds of deaths would be expected. No such outbreaks were reported. The authors suggest that black populations possess a dengue resistance gene (Halstead, 2001).

Further ethnic correlates of dengue disease have been documented in Cuba and Columbia. During the 1981 Cuban DEN1 outbreak, for each African descendent with DHF/DSS there were 5.5 individuals of European descent and 1.8 people of multiple regional descents who died from DHF/DSS. There were similar observances during the 1997 and 2001 outbreaks (Guzman et al., 1990; Sierra et al., 2007). DEN1 and DEN2 lymphoproliferative responses between ethnic groups were found to be statistically significant. European descended individuals showed higher dengue virus specific and heterologous IFN than African descended populations. The authors concluded that ethnicity plays a role in resistance to DENV (Sierra et al., 2007). A study investigating serum levels of cytokines in two ethnic groups in Colombia found higher rates of DHF and hospitalization in Mestizo populations in comparison to Afro-Columbians. This was partially attributed to the significantly higher levels of TNF alpha levels in Afro Columbians than Mestizos (Resprepo et al., 2008).

In a recent study, Ronald Blanton et al. (2008) used ancestry informative markers (AIMs) to test whether African ancestry is protective for severe dengue in Salvador, Bahia, Brazil. Blanton and colleagues' sample population included 55 individuals with confirmed or suspected DHF. These 55 individuals were asked to solicit four neighbors who reported having classic dengue (n=293) and four who reported to have never experienced symptoms of dengue (n=294). To estimate ancestry, 30 ancestry informative markers and 282 unlinked single nucleotide polymorphisms (SNPs) not associated with the clinical presentation of dengue were genotyped. Corresponding genotypes for 60 individuals from the Nigerian Yoruba ethnic group and 60 ethnic Caucasians were obtained from the Hapmap Project database and included for comparison and to improve the ancestry estimates. Self declared

black race, a higher percentage of African ancestry as determined by AIMs, correlated with the lower risk of DHF (Blanton et al., 2008).

The hypothesis that African descendent populations are resistant to severe dengue infection assumes ancestors living in regions with endemic yellow fever (YF). In the Americas, many individuals of African descent may trace their ancestry to West and West Central Africa and arrived in the Americas via the Middle Passage during the Transatlantic Slave Trade (TAST) (Fields, 1985; Eltis, Behtendt, Richardson & Klein, 1999; Gomez, 2004; Hall, 2007). West and West Central Africa is a region of the world that has prehistorically, historically and currently been documented to be endemic with YF (Strode, 1951; Kiple & King, 1981). Similar to dengue virus, YF is a *flavivirus* and is transmitted by the *Aedes aegypti* mosquito (Strode, 1951). It is hypothesized that within ancestral West and West Central African environments selective forces enabled some individuals to survive YF infection. These YF survivors were able to pass their resistant genes to future generations and currently may confer immunity to dengue. Host resistance is hypothesized to account for the low rates of dengue fever in West and West Central Africa despite the presence of the disease vector (World Health Organization, 2002; Blanton et al., 2008). Host resistance is also hypothesized to account for low rates of dengue in African descendent populations living in American tropical environments (Halstead et al., 2001; World Health Organization, 2002).

Researchers have used accounts of historical surveillance efforts describing African descendent populations as experiencing lower YF mortality and as a result, were able to assist during public health efforts (Hirsh 1883; Kiple & King 1981). Discussing the YF epidemic in Memphis during the 1870s, Gerald M. Capers provides epidemiological data illustrating that a higher percentage of African descendent populations may have an innate resistance to YF. He reported that in comparison to 75% of European descended populations dying from yellow fever only 7% of African descended populations died (Capers 1938:157). In 1952, *Science News* published a column entitled "Immunity to Viral Ills" reporting that in comparison to Europeans "in Africa certain tribes have immunity to the prevalent strains of yellow fever viruses" and evidently have the dominant gene for yellow fever immunity (Science News, 1952:303).

Similar to YF, historical field studies have also developed hypotheses correlating race resistance to dengue. According to Robert Bartholow, "The disease occurs in all ages and in both sexes, but the negro race seems to be, although not exempt, somewhat less susceptible, while mulattoes are attacked equally with whites" (Bartholow, 1898:847). In 1883 August Hirsch described in the *Handbook of Geographical Historical Pathology: Volume 1 Acute Infectious Disease* the influence of African heritage on resistance to dengue virus. Hirsch discusses how in the 1827 West Indian epidemic, African descendent populations "had the sickness more rarely and mildly" (Hirsh 1883:73). During an epidemic in Bangazi, Lybia in the 19th century there was a "remarkable immunity experienced by the blacks" (Hirsh, 1883:73). According to George F. Shrady, "Africans are less subject to dengue virus than others and have it lightly (Shrady 1891:660).

Current clinical and immunological data based on samples obtained from Latin America and Caribbean dengue patients suggest a lower morbidity and mortality, and suggest that the immune response to dengue virus in some African descendent populations may vary slightly (Guzman et al., 1990; Halstead et al., 2001; Brown et al., 2004; Seirra et al., 2007).

Consequently, hypotheses similar to those of historical researches are again being raised that lower dengue morbidity and mortality results from a possible innate genetic resistance (Halstead et al., 2001; Sierra, et al., 2007).

Human Variation and Dengue

There is compelling evidence that some genetic resistance to severe forms of dengue may exist. However, the lessons learned from the Tuskegee Syphilis Study should cause researchers to be cautious in how they proceed when investigating this phenomenon. At present, very little is understood, from an immunological or genetic perspective, on what causes one individual to be more susceptible and another more resistant (Pang, Cardosa and Guzman, 2006; Noisarkran & Perring, 2008). Approximately 1–10% of symptoms may progress into the more severe forms of DHS or DSS. Furthermore, reported epidemiological data on dengue prevalence, incidence, morbidity and mortality is poor, which can largely be attributed to poor public health infrastructure and equally poor diagnostics (World Health Organization, 1997). Thus, there are many unknowns that must be investigated prior to accepting any hypothesis that characterizes an entire racial group as biologically resistant. With so many unknowns a more cautious hypothesis is warranted.

The investigation of population sub-structure is one approach that may be taken to avoid racial analyses. Many researchers are beginning to look at within group variation and documenting how understanding sub-structure is potentially critical when predicting disease outcome. In an article investigating ancestry among European Americans Price et al (2008) stated:

> European Americans in fact form a structured population due to historical immigration from diverse source populations. This can lead to population stratification to systematic ancestry differences and to ancestry specific disease risk (Price et al., 2008: 9).

African descendent populations in the Americas also represent a highly diverse segment of the population having experienced historical migrations contributing to their diversity. According to Barbara J. Fields upon initial arrival to the Americas:

> The slave ships included Africans of different national, cultural, and linguistic backgrounds. Slave-buying planters talked in voluble, if no doubt misguided, detail about the varied characteristics of Coromantees, Mandingoes, Foulahs, Congoes, Angolas, Eboes, Whydahs, Nagoes, Pawpaws, and Gaboons. Experienced buyers and sellers could distinguish them by sight and speech, and prices would vary accordingly. Black people, in other words, were initially no more a racial group than Hispanics (Fields, 1982: 145).

Possessing this initial variability upon arrival, Africans did not stay in one location or exist in isolation. According to Robert S. Schwartz:

> After 400 years of social disruption, geographic dispersion, and genetic intermingling, there are no alleles that define… black people… as a unique population or race. Nevertheless, the prevalence of certain alleles

does vary among populations. In some cases, these variant genes originated as mutations that proved advantageous under particular environmental conditions. In central and western Africa…several independent mutations in the Beta-globin gene gave rise to different sickle hemoglobins, each with a distinct geographic distribution and phenotype. These mutations spread through the populations because they were protective against malaria, they were dispersed in Greece, Saudi Arabia, Turkey, Iran and elsewhere by migration and slavery (Schwartz, 2001:1393).

The above quotes are of direct interest to researchers hypothesizing that the African descendent population is resistant to severe forms of dengue. Any genes found that might result in protection from severe dengue must not be viewed as a black racial group gene. While some genes may circulate at a higher frequency, it is not valid to assume that all African descendent individuals are identical and possess identical genetic constitutions. Additionally, due to mixing with other non-African populations upon arrival in the Americas, it is likely that populations who are not identified as African descendent may also possess genes conferring genetic resistance to dengue. Simplistic racial analyses will prevent these complexities from being explored further. Thus, while epidemiological data have displayed a pattern, it is possible that to understand further the intricacies of this observed resistance further investigates are warranted.

Recent investigations of the differential response to malaria among the Fulani and Mossi ethnic groups in Burkina Faso illustrates disease outcome can exist beneath a simple racial level. Previous comparative studies on the susceptibility to malaria performed in West Africa showed that Fulani are more resistant to Plasmodium falciparum malaria than other sympatric ethnic groups and that this resistance is not associated with classic malaria resistance genes (duffy antigen/sickle cell trait). Torcia and colleagues (Torcia et al., 2008) explored the hypothesis that T-regulatory activity could be central in the control of malaria infection in populations exposed to naturally increased levels of *P. falciparum* transmission. They tested to see if an imbalance between specific effector functions of the immune system could be responsible for the high response to *P. falciparum* antigens and if this could account for the differences in susceptibility to malaria infection. Among the Fulani there was an increased expression of T-helper related genes and Th2 related genes and a reduced expression of genes distinctive of T-regulatory activity. Microarray analysis of genes involved in immune regulation indicated differences between the two ethnic groups. In parasitic infections, natural and adaptive T-regulatory activity preserves host homeostasis by concentrating excessive immune responses, however they can favor pathogen survival and pathogen persistence. The functional deficit of T-regulatory activity could be involved in lower susceptibility to malaria among the Fulani (Torcia et al., 2008).

If a simple racial approach were instituted in this analysis of malaria resistance/susceptibility, the comparison of these two African ethnic groups would not have occurred. To a certain extent, the analysis presented by Torcia's group does represent a movement away from traditional racial models of health and disease. Now that this biological variation has been established and documented to have an effect on health outcome, what are the reasons why two populations living in close proximity to each other have differential responses to malarial infection? It is through an analysis of historically relevant cultural and environmental variables where this question could be explored.

Traditionally, the Fulani are nomadic, pastoralists, and traders who herd cattle, goats and sheep. The Mossi are primarily farmers raising millet, sorghum, maize, sesame, peanuts and indigo. Analysis of the cultural practices of these populations evidences how cultural interactions with the environment may have led to the biological differences between the Fulani and Mossi. As herders, the Fulani alter their environment allowing for a high number of areas that are conducive for the breeding of the *Anopheles* mosquito, the vector responsible for the transmission of the malaria parasite. The regions in West Africa where the Fulani reside (Mauritania, Senegal, Guinea, The Gambia, Mali, Nigeria, Sierra Leone, Benin, Burkina Faso, Guinea Bissau, Cameroon, Côte d'Ivoire, Niger, Chad, Togo, the Central African Republic, Ghana, Liberia the Sudan) contain stagnant water that is used to allow the cattle, goats and sheep to drink from. The Mossi, on the other hand, are agriculturalists, and water is scarce resulting in cultural practices that include water storage technology and efficient use of water. It is possible that in the ancestral past and during the life course, the Fulani have been exposed to a higher number of mosquitoes potentially causing malaria. Through natural selective processes, historically those individuals who were able to survive malarial infection survived to reproductive age and passed these genes conferring resistance to descendant populations. This process allowed for descendent populations to experience less severe infection and lower mortality. In comparison, as a result of less accumulating water, the Mossi may have less mosquito exposure and experienced fewer malarial infections leaving them more susceptible currently.

A holistic analysis combining local and historically relevant cultural and environmental data with genetic data can assist when moving away from simple racial analyses. Currently researchers are beginning to correlate this host–pathogen interaction and the resulting genotype of the host. Differing from pathogens, whose genotype is comparatively smaller and less complex, the human genotype is large (20,000–25,000 genes), complex, and the result of thousands of years of evolutionary processes. Human evolution is characterized by the existence of many locally differentiated populations who coexisted with sufficient contact so that all of humanity is a single linage. However, it is the local differentiations that result in variation and corresponding resistances and susceptibilities to disease. Studies of genetic variation as it relates to dengue illustrate that regardless of race, across many global populations, individuals possess polymorphisms (SNPs or alleles) potentially conferring immunity while others possess polymorphisms potentially conferring susceptibility.

Genes targeted for analyses in genetic epidemiological studies code for proteins that are involved in the host immune response to a particular pathogen (antigens, cytokines, etc.). Researchers strive to determine whether polymorphisms or sequences in the genetic code result in variations in protein structure and function. Understanding human genetic variation and how it correlates with disease severity provides a new way to improve vaccine development, diagnostics, patient prognosis and can also pave the way for innovative curative approaches (Cassanova & Abel, 2007). In vaccine and drug development gene sequence data can be used when predicting the risk that a vaccine might result in "self" immune reactions against host epitopes. Immune responses against a pathogen antigen can cross react with host antigens of homologues that exist in the primary amino acid sequence or structure potentially leading to damage in the host tissue. Thus, understanding the human genome sequence combined with methods of predicting B-cell and T cell epitopes can facilitate screening for the presence of homologues between candidate vaccine antigens and proteins

in humans. This type of research could potentially allow issues with autoimmunity and cross reactivity to be tackled (Selib, Dougan & Rappouli, 2009).

However, current genomic research illustrates that the genetic code (genotype) cannot be immediately inferred to the phenotype. Thus, when defining the function of genes it is necessary to also understand the environment in which the genes are set (natural ecosystem, culture, nutrition etc.) and in which the organism and populations live and are selected (through evolution and life course) (Cassanova & Abel, 2007). An important characteristic of infectious diseases among humans is that throughout history there is considerable inter-individual phenotypic variability ranging from asymptomatic to severe infections (Cassanova & Abel, 2007; Ntoumi & Kwatowski, 2007). This difference in resistance/susceptibility illustrates the functional diversity of the immune response (Burgner, Jamieson & Blackwell, 2006). To date, the environmental and cultural variables in which genes operate have been largely ignored in many genetic epidemiological studies (Burgner et al., 2006). When investigating these variables, huge variations are observed in individual disease outcomes following exposure to pathogens.

There is currently an increasing awareness that the approach to deciphering genetic causes of disease must be holistic and multidisciplinary. While an individual's genotype may suggest a specific trait, intermediates including environment, history, demography, and host immune status influence the corresponding phenotype (e.g. DF, DHF/DSS). Understanding how these intermediates influence the genome constitutes the field of epigenetics. Epigenetics include any process that alters gene activity without changing the DNA sequence. Epigenetic processes lead to modifications that can be transmitted to daughter cells. Many illnesses, behaviors, and other health indicators already have some level of evidence linking them with epigenetic mechanisms, including cancers of almost all types, cognitive dysfunction, and respiratory, cardiovascular, reproductive, autoimmune, and neurobehavioral illnesses. Known or suspected drivers behind epigenetic processes include many agents, including heavy metals, pesticides, diesel exhaust, tobacco smoke, polycyclic aromatic hydrocarbons, hormones, radioactivity, viruses, bacteria, and basic nutrients (Weinhold, 2006). For example, researchers are beginning to investigate chromatin modification and how it influences the early events of viral replication cycles. Chromatin, a complex of proteins (histones) and DNA that is tightly bundled to fit into the nucleus, can be modified by substances such as acetyl groups, enzymes, and some forms of RNA such as microRNAs and small interfering RNAs. Modification alters chromatin structure to influence gene expression. In general, tightly folded chromatin tends to be shut down, or not expressed, while more open chromatin is functional, or expressed (Weinhold, 2006). It is anticipated that research investigating chromatic modification may assist in providing therapeutics to develop strategies to block initial interaction between host and pathogen that lead to infection (Harborth et al., 2003; Nair et al., 2005; Ang, Wong, Ng & Chu, 2010; Wu et al., 2010; Mukherjee & Hanley, 2010).

Across all populations living in endemic dengue environments there is variation in the severity of symptoms. It is increasingly clear that many complex diseases show genetic heterogeneity and often different locally defined ethnic determinants for the same disease operate differently in varying ethnic groups (Burgner et al, 2006). The analysis above of the Tuskegee Syphilis Study illustrates that when investigating ethnic group variation, it is important to move beyond race. As noted by the differential patterns of malaria resistance

and susceptibility between the Fulani and Mossi, local environment and culture influences the immune response between these two sympatric ethnic groups. If a racial approach were taken, this variation would have been overlooked. In regards to dengue, it is important to remember that some African descendent populations may be at risk of severe dengue and not all non-African descendent populations experience severe dengue infection as many cases are asymptomatic and mild/moderate. Studies that have provided documentation of asymptomatic and/or mild/moderate cases worldwide reveal that many individuals representing many ethnicities are often asymptomatic or have mild/moderate dengue symptoms. In a cohort study investigating the incidence of dengue in Bandung, West Java, Indonesia, during a two-year period (2000–2002) there were a total of 16 asymptomatic and 90 febrile dengue cases out of a total of 2,356 recruited volunteers (1501 men and 1035 women) (Porter et al., 2005). In terms of dengue, regardless of racial categorization, these 16 Indonesian individuals may be genetically similar to those African descendent populations in Latin America and the Caribbean whose symptoms are asymptomatic or mild/moderate. This hypothesis automatically eliminates the racial approach by defining individuals by the severity of symptoms. The next step would be to determine, in specific geographical locales, the cultural, environmental, and biological variables that may influence the progression to severe and or asymptomatic/mild dengue infection.

Analyses of the phenomenon of lowered risk to severe dengue in African descendent population must not take a racial approach. This does not suggest that this noted observation should not be investigated. If there is suggestive evidence that African descendent populations are more resistant, this information may prove useful to dengue vaccine and diagnostics development. However, a racial approach will neglect potentially important population substructure and its relationship to symptomatology. Variation in dengue symptoms is a typical observance (Thailand, Indonesia etc), and as stated above, only 1–10% of symptoms progress to DHF/DSS. It is possible that dengue risk among African descendent populations living in tropical regions is closer to 2% while the risk of infection in parts of Southeast Asia is closer to 8%. This is all within the normal range of 1–10%. It is also possible that the 2% of African descendent individuals may be similar to the 8% of Southeast Asian individuals whose symptoms progress to DHF/DSS. This reasoning would not be considered if adhering to a racial approach.

Discussion

This article emphasizes that a contextual analysis of the Tuskegee Syphilis Study can assist current researchers avoid identifying race as a significant variable when predicting health outcome. From a social perspective there is a lack of consensus about how race should be defined and exactly what it means (Ellison et al., 2007). From a biological perspective, humans share 99.9% of their genetic makeup, regardless of race, but most of the variants that occur in the remaining 0.01% of the genome are shared between whole populations (Weigman, 2006). Simply stated, there is more genetic variation within a racial group than between racial groups.

While race is currently documented to be an inaccurate concept that masks the underlying etiologies of disease, a large contingent of health researchers and practitioners continue to employ it as a variable. In current clinical practice physicians use their patients' skin color or other physiological features as a first step towards 'individual' treatment, under

the assumption that specific traits cluster by race (Weigman, 2007). In his article "The Misuse of Race in Medical Diagnosis" Richard Garcia states that medical education teaches that knowing a patient's race assists physicians in making diagnoses: "Doctors look at the patient's skin color, hair, nose, lips…and define ancestry in a single word: Asian, Hispanic, white, African American" (Garcia, 2004:1395).

Due to the tenable nature of race it is important to remember that, when used, phenotypic measures can only be a first step when identifying health outcome. For example, if a forty-five year old African American man entered a doctor's office, it would be negligent if the physician did not take this patient's blood pressure. Within the United States, the risk of hypertension and other cardiovascular diseases among African Americans is high and the failure to monitor blood pressure on this patient may result in further disease complications and even pre-mature death. However, hypertension and other cardio-vascular diseases are an end point and the actual underlying etiology of this disease state remains largely unknown. As more research is conducted on the underlying causes of why African Americans are at a higher risk of hypertension, researchers must actively move away from macro-racial groups and focus on within group variation. According to Lee, the problem with using race is that (Lee, 2005):

> If you look for differences, you find differences. What becomes the central question is whether a difference is significant… The danger is that scientists might uncover genetic differences with disproportional frequency between different groups and then incorrectly extend these results to broader racial groups; thereby strengthening the misconception that race is a biological category. This could have an impact on how differences in health status between racial groups are interpreted.

It is unlikely that higher resistance to dengue will result in 19th and early 20th century characterizations of African descent populations as inferior. In the racialized context that the Tuskegee Syphilis Study developed and initiated, racial differences were believed to result from evolution in ancestral continental homelands. Physical and behavioral racial differences were fixed and represented adaptations to continental environments. These adaptations resulted in four or five mutually exclusive and homogenous racial populations (Black, White, Asian, and Native American etc). Current evolutionary theory dictates that human variation cannot be explained in terms of continents since continents are vast with micro-level regional environmental differences. Furthermore, humans are not characterized as passive receivers of selective events resulting from environmental stressors. Local cultural practices often work to modify environments to the benefit of populations. According to Laland and colleagues (2010):

> Accounts of human evolution frequently assume that the selective events that shaped us were changes in the external environment, stemming from events beyond human control… This traditional conception of human evolution is now being challenged by recent anthropological studies that show that human cultural practices have modified environmental conditions, triggering changes in allele frequencies (Laland, Odling-Smee & Myles, 2010)

Thus, in addition to regional environmental differences within continents, the cultural practices by which humans actively participate in adapting to their environment also vary. Since evolution is constantly occurring, the study of human variation in regionally specific geographic locales in which people are living (life history) must also be included.

The malaria example above illustrates how the differing cultural practices of the Fulani and the Mossi influence the environment and their corresponding biology (as they relate to Malaria infection). The same micro-level analysis can be applied when attempting to investigate the hypothesis of increased resistance to severe dengue among populations of African descent. If yellow fever is identified as the selective driver of resistance, then is it valid to assume that all the ancestors of individuals of African descent were exposed equally to yellow fever in the past? West and West Central Africa is a very large geographical area with countless environments and ethnic groups. Within the context of current evolutionary theory, the idea of equal exposure to yellow fever in the past grossly underestimates and neglects the complexity of the African environment and the ethnic groups living therein. Furthermore, are the descendents of West and West Central Africans living in Latin America and the Caribbean genetically identical to their ancestors bought to the Americans during the transatlantic slave trade in the 18th and 19th century? The answer to this question is obviously no.

> Enslaved Africans did not exist in isolation but rather interacted with those already residing in Americas (Europeans and Native Americans) as well as future migratory populations (South Asians, Asians, Europeans, etc.). The exact African ethnic groups from which African descendent populations originated from, as well as the populations with whom they procreated in Latin America and the Caribbean solely depends on the geographical region in which they settled (Leslie, 2011).

It is unlikely that studies characterizing African descendent populations as having a monolithic genetic trait providing protection from severe dengue infection will result in a characterization of inferiority. However, many health care workers do not participate in the research process and may not be aware of the intricacies involved with the genetic correlates of disease resistance/susceptibility. It is true that any genetic trait must be documented to improve public heath efforts by identifying correlates of protection for vaccine development. However, until this is done, it is possible that misinformation about genetic resistance among African descendent populations may come to predominate and that this characterization may result in misdiagnosis and misguided public health efforts. If this becomes a commonly believed idea, then an African descendent individual with dengue seeking medical attention may ultimately be misdiagnosed based on their alleged racial appearance. On a population level, characterizing African descendent populations as low risk could potentially result in curtailing public health efforts in certain neighborhoods and communities. Due to the nature of transmission of dengue virus, this neglect potentially puts more individuals at a higher risk since the *Aedes aegypti* mosquito is not discriminatory.

Therefore, there are multiple steps that can be taken to avoid racial explanations of disease causation. First, in depth explorations in specific geographical locales must be made. This includes analysis of population migration patterns, local culture, local environmental

variables and epidemiology. After there is an understanding of the population within a historically relevant cultural and environmental context, local biology can be documented in relation to the disease under investigation. Finally, comparisons should be made across populations as it relates to the disease under investigation. For example, the 16 Indonesian individuals who had asymptomatic dengue infections could be compared to specific populations throughout Latin America and the Caribbean who also had asymptomatic/mild dengue symptoms.

Conclusion

This article has used the Tuskegee Syphilis Study to contextualize current research investigating dengue resistance among African descent populations. Through this contextual analysis it was emphasized that, while there may be underling genetic causes for this resistance, research investigating this phenomenon must move beyond the initial observation that African descent populations are resistant to severe dengue. A racial approach would mask underlying population substructure. More refined analyses must be instituted when conducting dengue disease surveillance and dissecting the correlates of protection necessary for optimal vaccine and therapeutic development and coverage. Thus the epidemiological characteristic that, in comparison to other populations, individuals of African descent seems resistant to severe dengue should represent an initial preliminary step. The next step should be the investigation of a possible innate resistance on a more refined level. This more refined level would include the analysis of different populations in different geographical locales who seem not to develop severe dengue. When investigating the possibility that resistance may have a genetic cause, the environment (natural and cultural) in which the host resides should simultaneously be investigated. Current genetic research illustrates that these intermediating factors have an influence on the host gene expression. This array of data will prove useful in current and future studies that may be used to predict the intricacies of the host immune response and how it may ultimately respond to vaccines, drugs and diagnostics used to prevent and control dengue. Eventually these data could allow physicians to determine whether a patient is genetically susceptible to a disease, the possible adverse effects of a vaccine or drug, and the appropriate schedule or dose to use (Selib et al., 2009).

As more information is gathered and technologies improve, race will prove to be an irrelevant means of predicting disease outcome. However, race is an important part of our identity and our culture. People racially identify and automatically racially classify others. Since science (medicine) is a part of culture, the culture of race finds itself into scientific theory and practice. According to Stephen Jay Gould:

> Science must be understood as a social phenomenon, a gutsy human enterprise, not the work of robots programmed to collect pure information…Science, since people must do it, is a socially embedded activity. It progresses by hunch, vision, and intuition. Much of its change through time does not record a closer approach to absolute truth but the alteration of cultural contexts that influence it so strongly. Facts are not pure and unsullied bits of information: culture also influences what we see and how we see it (Gould, 1996: 54).

Due to the pervasiveness of race, it is possible that the important micro-level data needed to analyze human variation outside of a racial context will be neglected into the near future. This directly evidences the significance of remembering Tuskegee Syphilis Study. When discussing Tuskegee, the racial overtones are obvious. When the Tuskegee Study developed and was formulated, ideas of race were paramount. Since we are looking into the historical past, it is often easier to observe and identify biases. This exercise becomes more challenging when critiquing and examining current research.

The process of moving beyond simple racial analyses will take time and a great deal of effort. Technologies will ultimately improve over time. However, if the theoretical climate remains the same and new ways of thinking do not evolve, data collection and analysis will not advance. Reflection on the Tuskegee Syphilis Study can assist in this process of moving away from simplistic racial explanations of human variability. The Tuskegee Study must not be viewed simply as an artifact, something we have learned from and could never partake in again. Historically, race was defined as important, and, while the assumptions underlying race differ today, it continues to be identified as an important variable of health outcome and is often employed as a proxy for human variation. Remembering and studying the Tuskegee Syphilis Study can assist when moving away from racialized approaches to the study of health and disease and inform new models of human variation and its corresponding influence on disease outcome. It is these new models of human variation that will advance the fields of vaccine, therapeutics and diagnostics development ultimately assisting in the prevention, control and elimination of dengue and other infectious disease.

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Community Health Advisors as Research Partners: Utilizing Community-Based Participatory Research to Address Cancer Prevention and Control in African American Communities in the Deep South

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Abstract

The idea of working with trained Community Health Advisors (CHAs) to bridge the cultural divide between the community and health systems is well documented. In fact, the literature is filled with studies that highlight the successes of CHAs conducting outreach activities and general awareness-raising events. Yet, few studies chronicle the processes associated with moving CHAs along the continuum of care to serve as a Research Partner. This article proposes to advance the CHA literature by describing the outcomes of the National Cancer Institute funded, Deep South Network for Cancer Control, a community-based, research program that involved CHAs trained as Research Partners (CHARPs) utilizing evidenced-based programs to improve breast, cervical, and colorectal cancer screening rates in medically underserved African-American communities in Alabama and Mississippi.

Keywords: African Americans, community health advisors, cancer prevention, evidenced-based, community-based participatory research

Introduction

While great efforts have been made in the past 40 years since President Nixon declared a "war on cancer," alarming cancer health disparities still exist in medically underserved African American communities in the Deep South, particularly in Alabama and Mississippi (National Cancer Act, 1971). The federal government and numerous other organizations have recognized the merits of funding programs that take a more tailored and systematic approach in reaching the medically underserved or those who have not been reached by traditional methods of outreach to increase age appropriate cancer screenings. The National Cancer Institute (NCI) funded Deep South Network for Cancer Control (DSNCC) is one such program that has been in existence since 2000 (Partridge et al., 2005). The goal of this program is to bring together academicians, researchers, network partners, and lay community members from targeted DSNCC communities to address cancer health disparities using evidence-based programs to increase cancer screening rates. The foundation of the DSNCC is the Community Health Advisors (CHA) Model, as well as capacity building and coalition development principles (Hardy, Wynn, Huckabee, Lisovicz, & White-Johnson, 2005). The purposes of this manuscript are to: 1) describe the formation of the multi-state DSNCC infrastructure; 2) showcase the development and implementation of a detailed Community Action Plan (CAP) to improve cancer screening rates in Alabama and Mississippi; and 3) illustrate how community-based participatory research (CBPR) principles were interwoven throughout the DSNCC to ensure adequate community representation, input, and ownership.

Snapshot of Cancer Burden in the Deep South

"Why is our state always at the bottom or the last in everything?" (Voice from the community)

The Deep South has the greatest burden of cancer disparities in the country. This cancer burden greatly impacts a region that is largely populated by African Americans (U.S. Department of Commerce, 2002). According to the *State Cancer Profiles*, there is an unequal burden of cancer in the Deep South from all cancer sites among all races (National Cancer Institute [NCI], 2011). In addition, states in the Deep South have the highest cancer mortality rates in the country. All six states in the Deep South that fall in the Mid-South Division of the American Cancer Society's (ACS) catchment area—such as Louisiana, Kentucky, Mississippi, Arkansas, Tennessee, and Alabama—are among the top 10 states with the highest cancer incidence and mortality rates (NCI, 2011). In addition to having the highest cancer mortality rates, Alabama and Mississippi also have the greatest number of African Americans experiencing cancer disparities.

Racial and Ethnic Cancer Disparities

"At first I was afraid to say the word cancer. I called it the "C" word because so many of my people had been affected by this disease." (A CHARP)

Racial and ethnic minorities in the U.S. experience higher cancer mortality rates than the rest of the population. According to the Alabama Cancer Facts and Figures, mortality rates for breast, cervical, and colorectal cancer in Alabama are substantially higher for African Americans than for whites (Breast: 32.0 vs. 23.6/100,000; Cervical: 5.7 vs.

2.4/100,000; Colorectal: 26 vs. 17.1/100,000)(ACS, 2008). The NCI (2011) reports that Mississippi experiences similar disparities (Breast: 35.8 vs. 22.4/100,000; Cervical: 7.5 vs. 2.4/100,000; Colorectal: 28 vs. 18/100,000). Cancer statistics from the ACS confirmed that African Americans continue to have poor chances of survival once cancer is diagnosed, suggesting the possible influence of co-morbid conditions and inequities in access to and receipt of quality health care (Jemal et al., 2004). Incidence rates are high for many cancers in African Americans secondary to factors such as tobacco use, poor nutrition, lack of physical activity and environmental exposures.

Cancer health disparities are influenced by economic, social, and cultural factors. According to Freeman (2003), these variables can affect prevention, early detection, diagnosis, treatment, post-treatment quality of life, survival, and mortality among African Americans. Addressing cancer health disparities requires a multi-faceted approach; particularly one that recognizes the interwoven relationship between the individual and their environment. The DSNCC serves as an example of a multifaceted program that takes into account individual, interpersonal, community and organizational systems, as well as public policy factors that impact participation in cancer screening.

Methodology

"Cancer: There is Hope" (A Key Message of the DSNCC)

The DSNCC purposely targeted the most impoverished and underserved areas in the United States. Specifically, the DSNCC focused its programmatic activities in 22 rural and urban counties in Alabama and Mississippi. The eleven targeted rural counties in the Alabama Black Belt are: Sumter, Greene, Hale, Perry, Dallas, Marengo, Lowndes, Choctaw, Bullock, Wilcox, and Macon. The urban county in Alabama is Jefferson County, which includes metro Birmingham. The eight targeted Mississippi Delta counties are: Grenada, Holmes, Humphreys, Leflore, Panola, Sunflower, Tallahatchie, and Yazoo. The two urban counties in Mississippi are Forrest and Jones, which includes metro Hattiesburg. According to US Census (2000), these counties were among the poorest in the nation and have high concentrations of African American populations. For example, in the Alabama Black Belt, an area stretching across the state's south-central counties and named for both its dark soil and the extremes of poverty among its African American population, the average per capita income is $12,691, ranging from $15,308 in Marengo County to $10,163 in Bullock County. Similarly, in the Mississippi Delta, 67% of the residents in this area are African American, and the average per capita income ranges from $10,749 in Tallahatchie to $13,786 in Grenada County. Jefferson County has a per capita income of $20,892 and 39% of the residents are African American. Approximately 30% of the residents of Metro Hattiesburg are African American and this area has a per capita income of $14,990.

Theoretical Framework

"We stand on the shoulders of our ancestors; strong men and women who did a lot with so very little." (Voice from the community)

Based on Paulo Freire's Empowerment Theory and the CHA Model (Freire, 1970), the DSNCC was able to harness the strength of the community by identifying natural

helpers and training them as Community Health Advisors trained as Research Partners (CHARPs). CHARPs played a vital role in the DSNCC Phase I, II, and III as they were able to facilitate behavioral and social change through natural social ties. Through an empowering and participatory process (Israel et al., 2003), the DSNCC staff made a concerted effort to actively involve CHARPs, community stakeholders, and researchers in joint decision-making ventures. While this was a timely process, the outcomes of our collaborative partnership enabled us to impact nearly every level of the socio-ecological model (see Figure 1), create a strong infrastructure that has been sustained since 2000, and produce outcomes that were meaningful to researchers, academicians, and more importantly the community (Glanz & Rimer, 2005; Stokols, 2009). Abbreviated DSNCC Phase I, II, and III outcomes are described below.
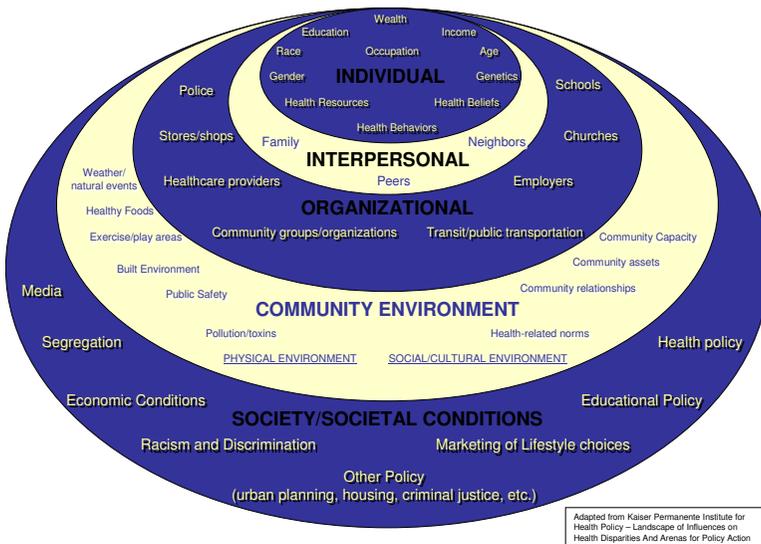
Figure 1. The Socio-ecological Model

DSNCC Special Populations Network Phase I Abbreviated Outcomes

"Give the community the tools to build a program and they will not only come, but invite others." (Voice from a DSNCC investigator)

Described in great detail elsewhere (Lisovicz, 2005; Partridge et al., 2005), Phase I (2000–2005) of DSNCC focused on implementing activities at the individual and interpersonal levels of the socio-ecological model. As an outcome of Phase I, the DSNCC established one of the largest cohorts of African American grass-root, community volunteer networks that has ever existed (to our knowledge) in both states. Specifically, staff recruited and trained more than 800 volunteers (CHARPs) in underserved areas of the Alabama Black Belt and inner-city Birmingham, Alabama, as well as the Mississippi Delta and inner-city Hattiesburg and Laurel, MS (Partridge et al., 2005). These volunteers were equipped and empowered to promote breast and cervical cancer screening in their communities and were supported by part-time, local UAB staff members who served as regional and county

coordinators. As noted in several publications, CHARPs played an instrumental role in changing breast and cervical cancer screening behavior (Fouad et al., 2006; Fouad et al., 2010), and advocating for increased funding for the CDC-funded Breast and Cervical Cancer Early Detection Program, as well as expanding Alabama's Breast and Cervical Cancer Prevention and Treatment Act of 2000 (Wynn et al., 2011).

DSNCC Community Network Program Phase II Abbreviated Outcomes

"The program with the same name, but an expanded mission" (Voice from a DSNCC staffer)

In our second round of funding as an NCI Community Network Partnership (2005–2010), the DSNCC CHARP pool was expanded to include not only CHARPs, but organizational representatives, and agents of change. The receipt of additional NCI funding enabled the DSNCC to implement programs at the organizational level and establish partnerships with community-based organizations and agents of change, such as school officials, government officials, pastors, and leaders of community based organizations. In additional to many noteworthy accomplishments, the DSNCC partnered with more than 50 different organizational partners across both states. Furthermore, under the guidance of American Cancer Society's Community Action Network, CHARPs and agents of change, initiated a massive grass-roots letter-writing campaign; successfully advocated for and secured an additional $400,000 for the Alabama Breast and Cervical Cancer Early Detection Program; had walking paths installed in some Mississippi Delta communities; and were instrumental in the adoption of a No Smoking Ordinance in Bessemer, Alabama, an urban city in Jefferson County.

While the first iteration of DSNCC produced promising outcomes, the community action plan focused primarily on cancer screening with a lesser focus on overall lifestyle changes. Based on findings from twenty-four discussion groups with CHARPs and community members, the DSNCC shifted its primary focus from cancer screening to a focus on lifestyle and behavioral change (Wynn et al., 2005). Specifically, the community felt strongly that the DSNCC should focus more on improving nutrition and increasing physical activity while simultaneously promoting participation in breast, cervical and colorectal cancer screening. Four working groups, comprised of a researcher, staff members, state-wide partners, and CHARPs, were formed to develop an integrated detailed Community Action Plan (CAP).

After several iterations of the CAP, four major evidenced-based strategies were adapted and tailored to meet the targeted communities' needs. Breast, cervical, and colorectal cancer messages were incorporated into each of the following programs as outlined in Tables 1–4.

Table 1. Abbreviated Overview of Physical Activity Program

Name of Program	WALK Feel Alive Program
Overview	The WALK Feel Alive program (WALK) is a physical activity walking program, adapted from the Minority Health and Health Disparities Research Center at the University of Alabama at Birmingham (UAB MHRC, 2007), that encourages individuals to increase their physical activity by walking.
	The overall goal of the UAB MHRC WALK is to promote healthier lifestyles in neighborhoods and communities by encouraging citizens to increase their walking by joining structured community-based WALK Teams. DSNCC adapted the WALK Feel Alive program to provide a structured walking program.
Objectives	1. Implement WALK campaigns in each county.
	2. Maintain local walking groups in each county.
	3. Use WALK as a research tool to educate participants regarding age-appropriate cancer screening practices.
CHARP role	1. Actively participate in walking group meetings.
	2. Complete necessary forms and return them to the designated team leader monthly.
	3. Agree to start walking as soon as they receive their team assignment.
	4. Agree to record steps using a pedometer.
Incorporation of cancer screening message	As part of the walking group activity, members canvass a neighborhood and personally deliver brochures and pamphlets to residents.

Table 2. Abbreviated Overview of Nutrition Program

Name of Program	Body and Soul
Overview	Body and Soul is an evidenced-based intervention for African American churches that has been shown to be effective in increasing church members' intake of fruits and vegetables.
Objectives	1. Implement Body and Soul campaigns in each county.
	2. Establish and maintain local Body and Soul campaigns in each church as a means of reducing one's risk of cancer while increasing fruit and vegetable consumption.
CHARP role	1. Plan, coordinate, implement, and promote the 4 Pillars of Body and Soul.
	2. Link the program to the congregation and pastor.
	3. Customize the program for the congregation based on needs of the membership.
Incorporation of cancer screening message	1. Insert health messages into the church bulletin and encourage the pastor to devote one Sunday a month to elaborate on the health message (while in the pulpit).
	2. Establish a health library or resource table in each participating church.
	3. At the beginning of each Body and Soul function, the team leader will read the health messages aloud and ask attendees to repeat what was shared; very similar to a "pledge".

Table 3. Abbreviated Overview of Cancer Awareness Program

Name of Program	Cancer Awareness
Overview	The goal of this program was to use successful community outreach strategies and scientifically valid health literature to promote awareness of and participation in breast, cervical, and colorectal cancer screening.
Objectives	1. Train CHARPs to encourage community members to participate in screening. 2. Train CHARPs to identify low screening areas by using data generated maps. 3. Establish and maintain local CHARP groups in each county. 4. Document activities that promoted community members' participation in screening, as well as overall successes and lessons learned.
CHARP role	1. Attend and participate in monthly maintenance meetings to continue their education and awareness of breast, cervical, and colorectal cancers. 2. Serve as a conduit of factual health information in their community. 3. Encourage community members to participate in screenings. 4. Submit the necessary forms and paperwork required.
Incorporation of cancer screening message	1. Disseminate approved brochures, pamphlets, and promotional items during the WALK campaign, Body and Soul, Direct Action Organizing, and individual/group contacts. As part of the walking group activity, members canvass a neighborhood and personally deliver brochures and pamphlets to residents.

Table 4. Abbreviated Overview of Advocacy Program

Name of Program	Advocacy
Overview	There are different methods of organizing in order to advocate for social or political change. Direct Action Organizing (DAO) is based on the power of the people to take collective action on their own behalf. The American Cancer Society Community Action Network (ACS CAN) served as the lead agent in this endeavor. NCI funds were not used to support any advocacy-related activities.
Objectives	1. Building on the expertise and experiences of our ACS CAN partners, translate their successes and lessons learned to the DSN DAO campaign. 2. Garner support for DAO among the CHARPs. 3. ACS CAN will use the train-the-trainer model to educate DSN investigators, staff, and CHARPs members about the processes involved in implementing a DAO campaign. 4. With leadership from ACS CAN, implement DAO campaigns in each county.
CHARP role	1. Dependent on the health issue facing the particular community.
Incorporation of cancer screening message	1. Disseminate approved brochures, pamphlets, and promotional items during advocacy campaigns.

Results

WALK Feel Alive Program Results

The WALK Feel Alive Program (WALK) was implemented in all 22 counties. One thousand eight hundred and sixty-six (N=1866) individuals were consented and enrolled into the 2-year WALK program with 216 WALK teams. It began in April 2007 and ran successfully for 2 years. Retention rates at 12 months were at 61% with a final overall retention rate of 51% at the completion of the program at 2 years. Unpublished baseline and 12-month surveys from the WALK teams demonstrated: a) increases in mammography screening at appropriate time intervals; b) increases in the receipt of mammography and sigmoidoscopy/colonoscopy screening among those self-identified as rarely screened; c) increases in physical activity levels; and d) increases in the number of servings of fruits and vegetables consumed daily.

Body and Soul Program Results

Not all DSN counties adopted the Body and Soul program (Resincow, 2004); 20 out of 22 counties chose to implement the program. Sixty-nine churches were selected to participate in the program, but only 53 churches enrolled. A total of 2,264 Health and Wellness surveys, which included self-reported cancer screening information, were completed by the Body and Soul participants. A major success of the Body and Soul program was the program's ability to disseminate cancer awareness messages and information to the African American congregations in remote rural areas. Unpublished DSNCC Body and Soul surveys showed aggregate increases in the number of servings of fruits and vegetables consumed daily.

Cancer Awareness Program Results

Over 1,579 community cancer education activities targeting individuals, systems, and agents of change were conducted by DSNCC CHARPs, partners, and staff. Through these educational and outreach activities, more than 118,112 individuals were informed about the importance of cancer screening and early detection. This number does not include those individuals who were reached via radio public service announcements (PSAs) and local newspaper articles. At the system level, cancer information messages were inserted into church bulletins, as well as beauty salons and local barbershops. DSNCC CHARPs regularly participated in the ACS Relay for Life. At the agent of change level, DSNCC program staff and the CHARPS conducted cancer presentations to members of the voter leagues, NAACP, as well as local and state legislatures.

The outcomes of these activities in collaboration with partners such as Alabama Quality Assurance Foundation, CDC-funded REACH 2010, and others lead to an increase in Medicare mammography screening rates in our targeted Alabama Black Belt counties. Screening rates in this select Medicare population were 30% for African American and 46% for whites at baseline (1998) before programs were implemented. In 2008 screening rates for both African Americans and whites were 58%. A disparity of 16% in rates for mammography was reduced to approximately 0%.

Advocacy Results

The CHARPs, under the guidance of the ACS CAN, participated in 21 advocacy-related activities for policies to support cancer screening funding through the state legislature and No-smoking ordinances. Other public policy changes included: 1) the procurement of a $400,000 increase in funding for BCCEDP; 2) the installation of walking paths in communities in Mississippi; 3) the implementation of a No-smoking ordinance Bessemer, Alabama; and 4) the expansion of Medicaid Treatment coverage to all women with breast or cervical cancer.

Conclusion

"If the problem is in the community, the answer is in the community." (Dr. Gilbert Friedell, a physician who has devoted his professional career, of more than 60 years, to preventing and treating chronic illness and is renowned for his work in the field of cancer.)

The past and present DSNCC outcomes underscore the importance of involving community members in each phase of a research project. It is a known fact that evidence-based programs that are tailored and delivered by credible, trusted natural helpers can result in not only successful community engagement, but also increased community ownership. The DSNCC has been successful in conducting outreach activities and community research in areas that have been described as medically underserved, vulnerable, and special populations. This program also demonstrated that developing and implementing community-based programs must be approached from multiple layers with extensive human capital. Program members are staff working with individuals and local community organizations were vital to the successful implementation of this program.

The DSNCC is an example of a long-standing program that has been working in the same 22 underserved counties and urban communities in Alabama and Mississippi since 2000. During this time, the DSNCC developed a trusting relationship with members of the priority population while simultaneously learning valuable lessons from the community. Lesson one focused on the need to address long-standing health problems from a multi-faceted, ecological perspective. The second lesson learned stressed the value and the importance of the CHA model in transforming individual and societal behaviors at all levels.

While this particular approach is not the only solution, it continues to be one of the most promising models for improving health disparities in communities where traditional approaches have not been as successful. It is significant to note that some of the measures of impact may take decades to demonstrate as illustrated in the impact on Medicare mammography screening in the DSNCC targeted counties. The DSNCC will continue to utilize the expertise of CHARPs in more research projects because CHARPs have their fingers on the pulse of the community and have the community in their hearts.

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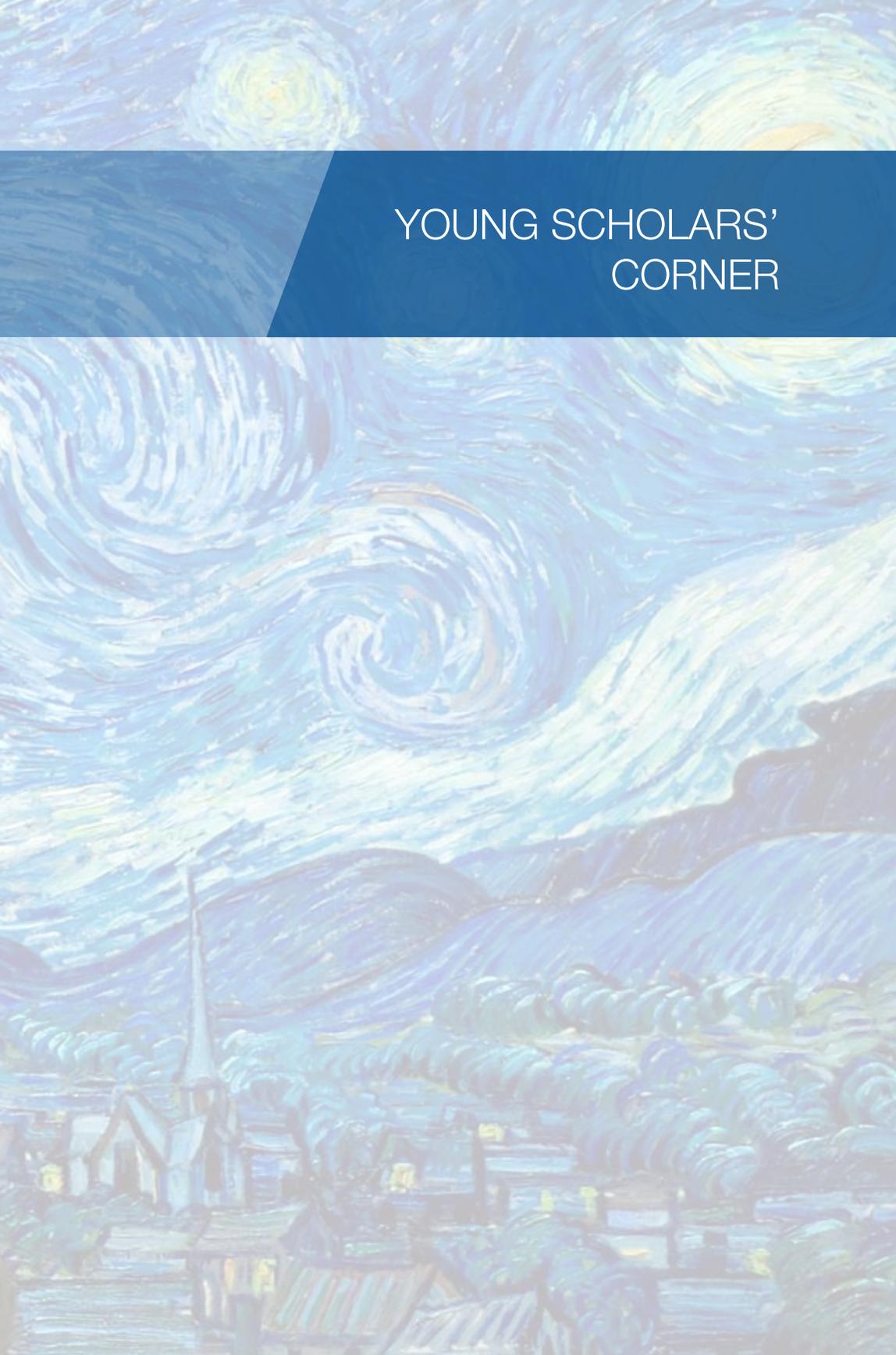
Treatment of Combat Fatigue from World War II to the Vietnam War within the U.S. Navy Medical Corps

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Abstract

This article explores the treatment and experience of combat fatigue, now known as Post-traumatic stress disorder, within the United States Navy and Marine Corps from World War II to the Vietnam War. The United States Navy Medical Corps introduced many therapies during this period, but forward-area treatment prevailed as the Navy's predominant remedy of combat fatigue due to its simplicity and relative ease of access. This article is divided into three sections: (1) World War II, (2) the Korean War, and (3) the Vietnam War. Each section is sub-divided into three components: (1) story, (2) terminology, and (3) treatments.

Keywords: Treatment of combat fatigue; Post-traumatic stress disorder, History of Navy Medicine

Young Scholars' Corner

Introduction

Post-traumatic stress disorder (PTSD) is a major psychiatric disorder affecting thousands of individuals returning from war zones. These young combat veterans maintain important societal responsibilities as they enter the work force and form families. It is important to understand their illness, as well as the treatments which alleviate their daily struggles with PTSD, so their personal disabilities do not prevent them and their families from living successful, happy lives.

Within the expansive literature written on military psychiatry and combat stress reactions during the twentieth century, the amount written specifically about United States Navy medicine is much less than its actual impact on combat veterans. Most books focus on the evolution of terminology or deliver splendid collections of first-hand accounts of veterans suffering from such disorders. Hans Binneveld's book *From Shell Shock to Combat Stress: A Comparative History of Military Psychiatry* includes chapters on the struggle to label the disorder, the origins and development of military psychiatry, but not one chapter was specifically devoted to the treatment of combat stress within the United States military. Moreover, Edgar Jones' and Simon Wessely's *Shell Shock to PTSD: Military Psychiatry from 1900 to the Gulf War* does, in fact, offer several chapter sub-sections on the treatment of combat stress within the United States military, but it does not focus on individual service branches. Finally, Richard Gabriel dedicates one whole chapter on American military psychiatry in *Military Psychiatry: A Comparative Perspective*, but primarily focuses on the United States Army. The latter books represent a sampling of the finest books written on military psychiatry, but they do not address the gap in the field, which this article chooses to explore. Most historical books rarely focus on the treatment of combat stress reaction, and to the best of the author's knowledge, none focus on the treatment of such disorders specifically within the United States Navy.

Military psychiatry has played a diverse role in the treatment of combat stress reactions and in the recruitment of healthy military personnel. In 1909, the topic of "crazy" people in the military was raised in an effort to emphasize the lack of preventative psychiatry. As a matter of fact, the "primary function of psychiatry in the armed forces…is to aid in the selection of efficient personnel, and to weed out those unfit from a psychiatric point of view" (Helgesson, 1941, p. 81). However, "the experienced line officer who has spent years in the service knows more about maintaining morale than the psychiatrist" (p. 81). Military psychiatry did not represent the most advanced line of thinking during its early twentieth century development (p.81); instead, it followed in the footsteps of crucial advancements in psychiatric theory and practice.

Before and up to World War I, military medical communities used varying phrases to capture the symptoms of each war's combat stress reaction. World War I was the first time that military medicine was called upon "to prevent and treat psychiatric casualties" in order to enhance the fighting strength (Glass, 1951, p. 1472). This change may due to new warfare methods, the use of mustard gas, trench warfare, and an increase in the population needing treatment. During this period, military physicians and officers maintained that shell shock could be attached more to the event than to the soldier's psychological response to the event. Shortly after World War I, the medical community established that the air blast on the head could not adequately explain the majority of the shellshock symptoms (p.1472). Following

World War I, the term "shell shock" emerged and carried the deleterious effect of associating war traumatic neuroses with cowardice and fear (Leed, 2000, p.95). Shell shock, however, fell out of use around World War II and was replaced by a more neutral, less moralizing term—"combat fatigue." From World War II to the Vietnam War, most military psychiatrists used the term combat fatigue.

The precursors to what is now known as PTSD finally came on the scene around 1950. The first incarnation of the *Diagnostic and Statistical Manual*, the DSM-I, was published in 1952 by the American Psychiatric Association. It introduced the diagnostic category of PTSD and classified the mental disorder as "Gross Stress Reaction" (DSM-I, 1952, p. 85). In the intervening years, the DSM-II referred to its corresponding diagnosis as "Adjustment Reaction of Adult Life" (DSM-II, 1968, p. 49). In 1980, the DSM-III introduced the diagnosis of "Post-Traumatic Stress Disorder" (DSM-III, 1980, p. 26). Various revisions and diagnostic criteria have been added to the DSM-III's definition and have then been taken up by DSM-IV (1994), DSM-IV Text Revision (2000), and in the much-anticipated DSM-V, which is set to appear in 2013. (See Appendix.)

Encapsulated in this rather brief history is a slow, but steady movement away from criticizing the soldier for failing to live honorably and toward treating him scientifically according to the best medical knowledge available. After War World I, military psychiatry has played a larger role in maintaining the health of the United States armed forces, including helping in the selection of recruits; identifying, diagnosing, and treating early disorders in training areas and combat zones; helping to improve morale among troops; and aiding veterans in the post-war period with readjustment to civilian life (Nolan, 1947, p. 59).

World War II

Story

Corporal Kristner (not his real name) was a good Marine and served as a leader in his platoon (Brown, 2002, p. 159). Within Fox Company and before the Battle of Iwo Jima, he knew his duties well and never hesitated to "execute them promptly" (p. 159). However, three weeks before Fox shipped out from Camp Tarawa for battle, "he withdrew from his common, daily associations in many respects and became a loner" (p. 159). After hitting the beach, his platoon was pinned down by a heavy Japanese machine gun (a Nambu) and remained stymied for at least one-half of an hour (p. 160). If anyone shifted around, the Nambu would release an unrelenting fire. To make matters worse, "no one could spot the location of the weapon" (p. 160). "Suddenly Kristner stood upright, pointing and yelling, 'There it is!' He was immediately felled by a hail of machine-gun bullets" (p. 160).

His battalion surgeon, Dr. Thomas Brown, later recalled a conversation about Kristner's death. One corpsman told him how Corporal Kristner received a letter which relayed how his wife was "chasing around back home" (p. 160). Upon receiving that letter, Kristner "became very morose and unsociable and lost his appetite" (p. 160). The threat of going into battle, not knowing if he would come out if it alive, in addition to the news of his wife "made him so dejected and indifferent about survival he had no compunction about sacrificing himself" (p. 160).

Terminology

Just as Corporal Kristner experienced the stresses of being deployed in a combat zone, Navy psychiatry would "re-learn" the basics of forward-area psychiatry through sheer volumes of combat experiences (Shephard, 2003, p. 205). These basics provided combat-deployed troops with access to psychotherapy and other forms of psychiatric therapy. One would expect the treatment of soldiers suffering from combat stress during World War II to be similar to the treatment applied during World War I, but this was not the case. The practice of medicine as well as the tenets of medical education evolved during the mid-twentieth century (p. 162). A more empirical conception of medicine, based on observation and practical approaches to behavior modification, evolved along with important developments in the basic medical sciences. The consequence of psychiatry's hanging on the coattails of medical science was that it was able to establish itself as a legitimate specialty, thereby to exert more authority in the diagnosis and treatment of mental illness.

At the beginning of World War II, medical communities insisted that the "emotional disruption occurring in battle was an acute traumatic neurosis" (Glass, 1951, p. 1472). The following misleading psychiatric disorders were applied to the subjects' reported conditions: psychoneurosis, anxiety state, anxiety reaction, psychoneurosis mixed, conversion hysteria, etc. Such overly broad nomenclature called for an improvement in military psychiatry, because these diagnoses did not capture the essential nature of combat stress reactions. Out of a "Tower of Babel," a new diagnostic category was created: "combat exhaustion." All branches of service modified the diagnosis to its own liking: "combat fatigue," "flying fatigue" and "operational fatigue" (p. 1473). As of yet, there existed no agreed-upon umbrella term that described the phenomenon; however, the air of fatalism implicit in the earlier conception had at least been removed. Unlike shell shock, fatigue was something brought on by the travails and grind of war and, also unlike shell shock, it could be treated through ordinary means. What a Marine with fatigue needed could be remedied; here then was a role for psychiatric medicine and for hospital staff to play.

An improved understanding of combat fatigue led to better diagnosis and treatment because it helped recognize the physiological origin of this disease as opposed to previously understanding combat fatigue as a "character flaw." Improved variation and availability of treatments corresponded to advances in neuroscience, specifically forward-area treatment, which also led to better treatment options for United States Sailors and Marines whom were treated by the United States Navy Medical Corps.

Treatments

In the treatment of combat fatigue, time of recognition was of the essence, and common sense guided psychiatrists' instructions. One *BUMED Medical News Letter* article discussed the correct method for evaluating neuropsychiatric causalities in the forward-area or "front lines." United States Navy Commander Robert Schwab presented fellow naval medical officers with a unique evaluation sheet that was designed to aid in the correct classification of neuropsychiatric patients (Schwab, 1944, p. 18). In short, the primary objective with regard to chronic fatigue was to "eliminate these patients from active duty, with their rehabilitation to civilian life as a secondary consideration" (Hamilton, 1944, p. 351). Navy physicians sought to maintain this protection and conservation of the Navy's

fighting strength by actively identifying early signs of fatigue. They did this by a full accounting of the soldier's inner life. Attention was now directed at widening the scope of inquiry from a singular event (shell shock) to the dynamic interplay between a patient's psychology and his experiences of war.

While field procedures were becoming more common, surgical procedures were new, experimental and relatively untested. Among the most promising, but also most ambitious was one known as the "lobotomy," a new psychosurgical procedure that first came to attention just prior to World War II. There was something quite intuitive about performing a lobotomy: cut one part of the brain off from the other in order to separate what is useful from that which is harmful. In practice, lobotomy involved severing the connection between the prefrontal cortex and the remainder of the brain (Shephard, 2001, p. 207). Lobotomy offered to patients the promise of doing away with their anxiety as well as the traumatic recurrences associated with their mental injury. The 1942 publication of *Psychosurgery* by noted American neurologist and neurosurgeon, Walter Freeman and James Watts, respectively, helped establish the credibility of the technique during wartime. They argued that lobotomies "separated the 'thinking brain' from the 'feeling brain' and thus removed 'the sting' from any psychosis. They freely conceded that the operation resulted in personality changes and that they had had failures but claimed that, on balance, it was worthwhile in certain intractable cases" (Valenstein, 1987, p. 172). If a soldier suffering from chronic combat fatigue could not return to normalcy, still it was hoped that some of his life—his rational life—could be given back to him.

Of course, among practicing psychiatrists, the procedure was controversial from the start. On the one hand, some realized that the condition was acute and that perhaps only a drastic solution would improve the patient's quality of life. On the other hand, some disputed the ethics behind performing this new technique: "'The psychosurgeon,' one [dissenting psychoanalyst] declared in 1949, 'is indeed treading on dangerous ground when he decides that a patient without a soul is happier than a patient with a sick soul'" (p. 182).

For roughly ten years, the lobotomy would have its day in the sun, aided in part by the availability of new drugs. Initially, the increase in lobotomies performed correlated with an increase in newly developed antibiotic drugs, yet the number of lobotomies began to decrease by the spring of 1954 when anti-psychotic drugs appeared to be considerably more effective and, at the same time, much less invasive (Clare, 1976, p. 338). In hindsight, lobotomies could be seen as an early, albeit failed, attempt by surgical medicine to restore mental health to those who have been so shaken by the tremors of war. And yet, the irony should not be lost— that the cure, in this case, could not have been much better than the ailment.

More effective than performing lobotomies, it turns out, was simply catching the illness early and treating it with decency and care by implementing "forward-area treatment." In a way, this required medical staff to see the condition in an entirely different light: in terms analogous to injuries. Patients would exhibit identifiable symptoms, have wounds, need treatment, and could be mended and repaired. And if all went according to plan, they could be brought back to the theater of battle more or less healed. A key article published in 1945 in the United States Naval Medical Bulletin spelled this new mindset out clearly. The authors described a fundamental factor for the treatment of combat fatigue for Marines

fighting on the "front lines." Although most of the combat causalities during the Pacific campaigns were diagnosed as combat fatigue, the specific forward-area treatment achieved nearly an 80 percent return to duty (Brunner et. al, 1945, pp. 611–620). This is significant because specific techniques for the treatment of combat fatigue observed in World War II sailors and Marines, such as "hypnosis, intravenous sodium Pentothal combined with narcosynpaper, and modified insulin therapy" all achieve an equal level of efficacy (p. 611). Forward-area treatment achieved a substantially higher level of treatment efficacy, and as such it represents something of an early breakthrough (p. 611).

One major limitation of the study was that it only included patients who had past histories that indicate strategies of healthy social adjustment and who were "free of psychoneurotic tendencies" (p. 611). Although the symptoms of combat fatigue vary from individual to individual, they can nevertheless be divided into two general groups: (1) symptoms of anxiety and (2) socio-psychologic symptoms (p. 611). Symptoms of anxiety can be reduced into an affect characterized by feelings of helplessness, impending danger, and overwhelming amount of stimuli (p. 612). Socio-psychologic descriptors include: marital status, economic status (occupation), educational level, position in the community, achievement, military rank, psychological makeup of the individual (affect/mood), or religious affiliation. Moreover, a study of 500 men suggests that the following disposition is typical of Marines suffering from combat fatigue: the patient is "quite upset by his experiences, he did not want any more battles for awhile—perhaps never again; if some more battles had to be fought, then somebody else ought to fight them; he thought that he ought to go home right away" (Crispell, 1944, pp. 16–19). In short, his anxieties ran high, and he had lost both his nerve and resolve.

Given this dark picture, then, it is striking how effective the new treatment was. What mattered most was time: most patients reached these forward-area hospitals following evacuation from the combat zone, with most arriving with less than ten days elapsing between evacuation from the beachhead and hospitalization (Brunner et. al, 1945, p. 612). Although, during transit, anxiety symptoms decreased, most patients initially experienced a worsening in socio-psychologic symptoms due to their separation from their closest allies, those with whom they had shared common experiences (p. 612).

Once they finally arrived at the forward hospitals, doctors could immediately detect profound fatigue: "they had been subjected to almost constant danger of injury and destruction, had worked hard physically, had had minimal rest and food, and had lived under extremely primitive conditions" (p. 612). The latter factors accounted for the anxiety conditions, but from where did the socio-psychologic features arise? Military units, especially those forward-deployed in combat zones, maintained close-knit relationships that could not be found elsewhere or were without substitute. However, an individual who experienced combat fatigue developed an "altered relationship to this group" and change in "position in the community" (p. 612). Under normal circumstances, an individual suffering from combat fatigue should, in time, become an efficient combatant once again. He felt at home with his group and found support there. However, if the bond between him and his fellows should weaken beyond repair, then he might end up becoming an isolated, frightened critic fed up with his companions in particular and with the war in general (p. 613). For someone suffering from combat fatigue, there was the wilderness and nothing else.

As one might expect, effective treatment of combat fatigue targeted both sets of problems; it acknowledges the roles that anxiety and socio-psychological symptoms both play and thus sought to remove an individual from the combat's environmental stresses, while also promoting a "psychologic re-orientation toward the group" (p. 613). In the case of anxiety, the aim was to re-acclimate the patient in everyday life, to make him feel as if the ground below his feet was actually stable. But how was this to be done? Hospitalization relieved patients from anxiety by mandating rest, cleanliness, adequate nutrition, and medical care. A typical patient's schedule looked like this:

0530-Reveille.

0545-Every patient polices his bunk, locker and immediate area.

0630-Breakfast.

0730-Sick call.

0800-Ward closed to patients who go for games, to workshop, work in garden, Red Cross building, or to assigned places within hospital compound.

1100-Return to ward; clean up for noon meal.

1130-Chow.

1230-Rest period on ward.

1330-Ward closed for 2 hours, same activities as at 0800, with addition of swimming parties twice weekly.

1530-Return to ward; clean up for evening meal.

1700-Chow.

1800-Rest and free period.

1900-Sick call.

1930-Movies, general hospital entertainments.

2130-Lights out.

Where war had brought shock and uncertainty, hospital life promised normalcy, discipline, and simple tasks to perform. In broad strokes, the homelike atmosphere of the daily ward-routine clearly amounted to a holistic treatment approach; the goals were to improve patient health and to allow him the time he needed to mentally adjust. The regimen, which consisted of cleanliness, orderliness, and deliberate friendliness, upheld proper military discipline while also making patients feel more at ease.

 In the case of "psychologic reorientation," the patient was to be immersed in sports (p. 616). The ward mandated that all patients had to actively participate in competitive sports, either as athletes or as spectators, or use the workshop:

By being encouraged to participate in sports…the patients soon feel a comradeship and before long teams and tournaments develop. It is remarkable to observe how quickly a disgruntled and dissatisfied patient will take an interest in a competitive sport, if he is properly approached… an active recreational and occupational therapy program…has a direct benefit in building up a man's self-confidence and creative ability (p. 616).

The therapeutic benefit of involvement in sports can be seen in the patients' feelings of self-satisfaction resulting from their participation in goal-directed activities, their belief that something truly matters, and their desire to do something with themselves. Additionally, he could take pride in acting in the world and with his peers without worrying about serious consequences. Finally, such activities had the added benefit of boosting the morale of the hospital staff and corpsmen when they actively participate with patients (p. 616). This latter point is significant because the authors of the 1945 article recognize that health care providers needed to remain healthy in order to continue to provide peak patient care.

During treatment at the forward-area hospitals, doctors often used sodium amytal to help patients explore their deep anxiety at the subconscious level. In fact, this drug allowed patients to relay information to the psychiatrist, which would otherwise be impossible to pry from the patient suffering from combat fatigue. In fact, sodium amytal had been widely utilized in the treatment of mental disorders (Susselman et. al, 1947, pp. 8–11). Sodium amytal was found to be effective at "probing and clarifying stuporous psychotic states and its value in alleviating major hysteria" (p. 9). It has been little used in the treatment of tension states, which remain the "largest category of the psychoneuroses."

Korean War

Story

James W. Evans was hard-working country boy who secured a job on a Mississippi River tugboat in the last years of high school to help his family earn money and "to follow the excitement of Mark Twain" (Evans, 2010, p. 12). He graduated from high school in Memphis, Tennessee to later enroll at Memphis State College in 1947 (p. 12). After graduating from United States Army Ranger School, Second Lieutenant Evans shipped to Korea in 1952. After spending several months surviving and leading Able Company through a range of fighting and bitter weather conditions, he received simple orders: "Get Able Company ready for a horrific battle" (p. 100). Outpost Harry was situated on the most direct route to the South Korean capital, Pyonggang, elevated, and was reinforced with fighting bunkers, trenches, artillery support, and thousands of Chinese enemy forces (p. 102).

When leading the reconnaissance team consisting of his executive officer, platoon commanders, and radio operators, he encountered the "destruction without comprehension" of Outpost Harry:

> "I saw what appeared to be an American soldier lying in the center of the trail…The soldier's body had been dismembered. From studying the scene, it appeared the tracked vehicle had run over the soldier several times. The tracks of the [vehicle] spread body parts from the man's crushed and mangled torso for several feet…Embedded in the dirt, parts of his spine were visible…It was a terrible sight…There was nothing we could do. Realities of combat once again hit home, and we all grasped the awfulness of where we were and what we could expect… I believe each of us, for an instant, visualized ourselves being in this soldier's condition. We gritted our teeth, took some deep breaths to keep from vomiting…We did the job we had trained to do. We went to war" (p. 108).

These realities of war and the images of the poor soldier lasted in their memories "forever" (p. 108). Even after the fighting stopped on 27 July 1953 and upon arriving home, Ranger Captain Evans faced the "trauma of returning to civilian life" (p. 108).

While living at home with his family and studying at Memphis State College, James' sister walked up to him from behind while he was searching through their refrigerator (p. 181). "Suddenly [he] whirled, hitting her across the room…For an instant it seemed [he] had been back in the trenches feeling a gun in my back. As [he] had killed with [his] bayonet, [his] reaction to protect [himself] was fast and beyond [his] control" (p. 182). James, of course, apologized to his sister and explained how he was not used to being out of the army (p. 182).

Terminology

Similar to United States Navy psychiatrists of World War II, those of the Korean War used "combat exhaustion' as the standard diagnosis to categorize acute psychiatric casualty" in cases where troops were operating in the forward-area (Glass, 1951, p. 1473). Navy psychiatrists operating in the forward-area also saw many patients with a variety of mental disorders. (Cole and Kolansky, 1951, p. 1540). Doctors quickly learned to disregard the intricacies of individual patients who suffered from anxiety reactions, and to "discuss directly with the patient the conflict of which the patient was at least partly aware" (p. 1540).

Treatments

In spite of the consistency of diagnosis when compared to World War II, the United States Navy Medical Corps began limiting the use of lobotomies (Treatment of Psychoses with Bilateral Ablation of the Frontal Cortex, 1949, pp. 13–15). Neuroscience researchers cautioned physicians in carrying out lobotomies; previous misunderstandings held that this operation carries "little risk… [but] transorbital lobotomy is not the harmless procedure that it is reputed to be" (Beardmore and Elliott, 1950, pp. 14–15). Moreover, even when performed under the strictest aseptic conditions, caution was still advised (pp. 14–15). Infections, fevers, and inflammatory reactions were common post-operative symptoms of transorbital lobotomies that significantly reduced a patient's chance of living after this already controversial procedure (pp. 14–15).

During the Korean War, the Navy Medical Corps capitalized on many lessons learned during World War II. An emphasis on forward-area treatment supplemented with psychotherapy characterized the treatment of sailors and Marines suffering from combat fatigue.

Navy psychiatrists gave every arriving patient an initial interview, which quickly removed the "veneer of symptomalogy" and revealed "the patient's fear of combat, [and] anger at a superior" (Cole and Kolansky, 1951, p. 1543). The psychiatrist placed great emphasis on this brief psychotherapy because it helped tie the patient's feelings to the direct and immediate source: the war itself. This treatment frequently lessened anxiety or, in some cases, caused anxiety to disappear altogether (p. 1543). Most of all, it helped the patient understand "what he was really concerned about" (p. 1543). Moreover, initial psychotherapy at the United Nations field hospital, where most cases were treated, proved to be especially effective because "rapid evacuation inhibited a complete establishment of the neurosis"

(p. 1543). Within the realm of psychotherapy, the Navy Medical Corps acknowledged that it must supplement conventional talk therapy with psychotropic medications. (See Appendix.)

When treating patients with conversion reactions, physicians administered large doses of coramine following an administration of sodium amytal. This combination of psychotropic medications removed nearly all symptoms of the conversion disorder and most patients could be returned to combat or noncombat duty within a short time frame (p. 1543). (See Appendix.) After a treatment, "almost all patients, rather than becoming gratified at being able to walk or see, would become hostile toward the therapist" (p. 1543). This was due to the initial shock of the elimination of anxiety symptoms (p. 1543). However, therapists discovered that this negative reaction would soon subside before the patient returned to active duty (p. 1543).

Similar to the forward-area treatment administered during World War II, forward-area treatment of the Korean War insisted on re-habituating patients to normal life. All patients were made to regularly clean up after themselves, shave, sleep, and eat. However, any patient suffering from "moderate anxiety reaction looked much improved after he merely cleaned up and had a good night's sleep" (p. 1543). Doctors conducted an outpatient psychotherapy session and interview:

> The emphasis in the interview and therapy was always on the current situation in combat and what was happening in the interpersonal relationship between patient and doctor. The patient was not allowed to use the cloak of symptoms with exploration of the conflict. We are much encouraged by our results using this form of psychotherapy (p. 1543).

Similar to treatments employed during World War II, United States Navy physicians during the Korean War valued the importance of eating hot meals and getting enough rest, or affectionately known by sailors and Marines as "three hots and a cot" (p. 1544).

During the Korean War, the primary psychiatry treatment center was part of United Nations field hospital. Such centralization of psychiatric casualties differed from the World War II, which used multiple independent psychiatric treatment centers (p. 1544). Several improvements in medical care arose because of this centralization.

> Some of the "mysticism" frequently cloaking psychiatric work in the minds of other doctors was removed by having psychiatric patients on their own wards…The importance of situational and psychogenic factors in causing illness was thus seen by the other medical men through consultations about their own patients. As a result of this liaison, the other medical men developed greater facility in diagnosing, treating, and returning to duty those on their own services who had psychologic factors in their illness (p. 1544).

This increase in awareness of the merits of psychiatric treatment became evident as the admission rates of patients to the psychiatric treatment center increased (p. 1544). Moreover, "almost all psychiatrists in Korea were known to one another," thus enabling them to discuss their mutual problems as practicing division psychiatrists (p. 1544). "This

[liaison between division psychiatrists] of course played a part in our record for returning large numbers of patients to duty" (p. 1544). Such close connections between fellow military physicians helped implement a presumably good rate of return back to combat.

An article in the *United States Armed Forces Medical Journal* presents a high rate of return to full duty, but there is no way to guage how well-recovered these patients were after receiving treatment: "The average hospital stay of patients was 2 to 3 days. 65 to 75 percent of them were returned to duty, of which about 45 percent went to full duty and the rest to limited duty" (p. 1544). Regardless of the actual mental states of returning Marines, it is fair to assume that the high rate of return can be primarily attributed to the highly centralized treatment centers:

> "Among the factors influencing the large number of returns to duty as compared to those in World War II, was the fact that although the treatment center was often 200 miles from the front, the rapidity of transportation by air was such that there was no long, slow trip back to a treatment center behind the division clearing stations…Lastly, the stay of only two or three days in the hospital decreases the time during which secondary gain might develop" (p. 1545).

Centralization played a clear role in improving the efficacy of psychiatric treatment among United Nations forces, including United States Marines, during the Korean War. Although World War II and the Korean War maintained many similarities with regard to the treatment of combat fatigue cases, they differed especially within the realm of centralization and an emphasis on psychotherapy.

Vietnam War

Story

In high school, Mike Harris was an above average student and a star full back on his football team (Dicks, 1990, p. 96). During his senior year with aspirations of enrolling at Oregon State University, the Vietnam War began to take on a "whole new focus" on the national stage (p. 95). Mike "weighed [his] options and decided to join the Navy for four years instead of being drafted for two" (p. 95). Overcoming the challenges of boot camp and qualifying as a Navy Radioman, Mike began his studies for radio school (p. 98). After graduating from "Radioman A School," he received orders for "Mobile Riverine Force, Republic of Vietnam" (p. 98). He grew up fast, as he quickly realized "every word spoken by [their] instructor…might save [their lives]" (p. 98).

He boarded the big Braniff jet straight to Tan Son Nhut Airbase in Saigon and was assigned to the River Assault Squadron 15. He also rapidly learned how to handle firefights: "In a firefight you shot as fast as you could. I screamed and yelled during these encounters and was surprised how I hung in there and poured out the lead. It was our only defense" (p. 99). One night in combat, one of his friends, Barry, was hit in the chest with a rocket, which splattered him everywhere. "All [they] could do was to put the pieces that were left of Barry into an empty 20MM can and dump it over the side. The larger parts were sent home to his parents" (p. 100).

His year-long tour ended and shortly thereafter was discharged from active duty. He saved up nearly six thousand dollars and was determined to "drink it away" (p. 101). He would sometimes "indulge in marijuana or other drugs" and "It was as if [he] were suicidal" (p. 101). "[His] life was taking a downward spiral at an accelerating pace" (p. 101). However, after several years, he experienced a "miracle" and his life slowly improved (p. 101). He joined the Point Man Ministry to help veterans suffering similar problems (p. 101).

Terminology

During the Vietnam War, the United States Navy Medical Corps employed similar treatments and maintained a similar nomenclature of diagnosis in relation to World War II and the Korean War. The United States Navy Medical Corps encouraged its physicians to use "combat fatigue" as the primary diagnosis during World War II, the Korean War, and the Vietnam War. During the Vietnam War, United States Navy physicians were issued a directive explaining, "to not label it [combat fatigue] yet as some sort of anxiety disorder or anything like that" (interview). Navy medicine could now speak a language of understanding and historical relevance.

Treatments

The forward-area treatment proposed by World War II psychiatrists, and used by Korean War psychiatrists, once again proved its usefulness during the Vietnam War. Dr. Stephen Edmondson, a Navy psychiatrist assigned to the United States Marine Corps Third Medical Battalion during the Vietnam War commented on forward-area treatment and the patients he saw:

> If [the patients] were really bummed out, psychotic, disorganized, or extremely fatigued, we just put them to sleep…Enough sleep for two or three days. I had instructed the corpsmen just wake them up from time to time, help them to the latrine, get some fluids into them, and see if they could get them to eat something, and then just let them go back to sleep.

> Usually after a day or two of rest, most of these fellows had drastically improved. And most of them were able to get back to their units. Our evacuation rate just dropped like a rock. And even when [the] big Khe Sanh siege was still going on up to the northwest of us, we were getting most of those fellows back to duty, too (interview).

A clear parallel between the effectiveness of the "three hots and a cot" treatment remains evident throughout the history of the treatment of combat fatigue. However, the introduction of new psychotropic medications helped revolutionize the treatment of such disorders, which were linked to actual chemical imbalances in the patient's brain.

After patients were referred from their units, Dr. Edmondson would corroborate the general medical officer's report with the patient's comments. This served to establish a rapport between the patient and physician. The high quality work of the unit's general medical officer also screened out "manipulators" who were only interested in being "shipped out of the country" (interview). Dr. Edmondson says, "There weren't too very many of those that I ran into" (interview).

He conducted an up-front interview which helped patients understand what they could expect from their psychiatric rehabilitation. He would talk things over with patients and tell them what he thought, especially whether or not the patient needed to get himself ready to go back to combat (interview). "This was particularly tough with some of the young men coming out of Khe Sanh, but most of them accepted quite well. And most of them did go back" (interview).

Dr. Edmondson observed in many patients who returned to the battalion office that they were glad to return back to their units, after being seen for their adjustment and other psychiatric disorders. He treated patients with a limited means: psychotherapy and administration of Thorazine. (See Appendix.) He sent back patients to their units with his assessments and recommendations; usually without any patients on medications. If patients needed medications, he would keep them for a few days. If patients stayed, they would receive "rest, no duty or light duty [orders], thorazine treatment, or whatever might be needed" (interview). According to Dr. Edmondson's interview, the main form of treatment during the Vietnam War was forward-area treatment that emphasized rest, complete meals, and psychotherapy. In other words, this primary form of treatment did not deviate much from the treatment used during World War II and the Korean War.

It is important to emphasize the prominent role that "three hots and cot" treatment served, which provided "rest, aided by the medication, and the food the corpsmen gave them, and support in a safe place—a relatively quiet place—got most of them turned around pretty quickly." Additionally, drug therapy made a prominent impact on the treatment of combat fatigue during the Vietnam War (interview). Such targeted treatment of brain chemical imbalances served as a key difference between psychiatric treatment during Vietnam and previous wars. The introduction of psychotropic medications to the arsenal of Navy psychiatrists grew out of pharmaceutical research of the late 1950's and afterwards.

Conclusion

Neuroscience within the United States Navy Medical Corps experienced a unique explosion of treatment options available to Marines and sailors suffering from combat fatigue from World War II to the Vietnam War. Although one primary aspect of treatment remained constant throughout all wars—adequate rest, nutrition and safety—Navy physicians helped introduce contemporary advancements in neuroscience to their patients in the frontlines. World War II introduced lobotomies, but the Korean War retracted their effectiveness due to concerns for biomedical ethics and patient safety. The Vietnam War introduced a more rigorous implementation of psychotropic medications, but due to limited access to prescription drugs, such treatments were not integral components within the treatment of combat fatigue.

Military psychiatry recognized that the unnatural, traumatic experiences of war have profound effects on combatants, so this field attempted to treat this disorder as they saw best. Specifically, the United States Navy Medical Corps devised an evolving treatment spectrum for combat fatigue within the span of three major wars: World War II, the Korean War and the Vietnam War. As neuroscience shifted its focus on the physiological, even empirical, aspects of combat fatigue via a changing diagnosis, treatment among sailors and Marines improved.

Appendix

Post-Traumatic Stress Disorder

The critical characteristic in Post-Traumatic Stress Disorder is the development of certain symptoms "following exposure to an extreme traumatic stressor" (DSM-IV TR). These traumatic events, or sources of trauma "include, but are not limited to, military combat, violent personal assault …, being kidnapped," and others (DSM-IV TR p. 463). Such extreme, life-threatening stressors often involve death or serious injury, threat to one's personal integrity, witnessing death or serious harm, or learning about the death of unexpected or violent death (DSM-IV TR p. 463). The person's response to the event "must involve intense fear, helplessness, or horror" (DSM-IV TR p. 463).

Individuals suffering from PTSD exhibit a constant avoidance of stimuli connected with the trauma and a numbing of general responsiveness. They may avoid thoughts, feelings, or conversations with the trauma; activities related to the traumatic event; "inability to recall an important aspect of the trauma;" unable to have loving feelings; feelings of detachment from others; "a sense of a foreshortened future;" and others (DSM-IV TR p. 465). Additionally, they show "persistent symptoms of increased arousal" (DSM-IV TR p. 465). In other words, people suffering from PTSD may have trouble sleeping, outbursts of anger, increased vigilance, exaggerated startle response, and others (DSM-IV TR p. 465).

In addition to the wide-ranging symptoms and diagnosis criteria, several specifiers help mental health professionals with diagnosing their patients. The "acute" specifier is used when the duration of symptoms is less than three months, whereas the "chronic" specifier is used when the symptoms last three months or longer (DSM-IV TR p. 465). Finally, the "delayed onset" specifier, which is common among returning veterans, indicates that at least six months elapsed between the traumatic event and the initial onset of symptoms (DSM-IV TR p. 465).

Barbiturates

Physicians prescribed barbiturates for the short-term treatment of insomnia; they also prescribed them when patients had trouble falling asleep or staying asleep (Longe Anti-Isomnia Drugs pp. 317–318). Barbiturates acted on the central nervous system to cause drowsiness, making patients relaxed, calm, and sleepy (Longe *Barbiturates* pp. 492–493). In the case of combat fatigue, one of the primary symptoms is restlessness. To aid in the recovery to a healthy life, psychiatrists have emphasized that patients remain well rested, so they prescribed barbiturates.

Phenothiazines/Hydroxyzine

The small unit focused its treatments "with the fairly heavy use of…a bottle of Thorazine" (chlorpromazine). Besides Thorazine, Navy psychiatrists could obtain mellaril (thioridazine) and vistaril (hydroxyzine) for acute anxiety and for sleep deprivation. They typically did not prescribe anti-depressants because patients could not be sent back to active duty so long as they were taking anti-depressants (interview). Operating in the front lines while needing a prescription for anti-depressants posed a difficulty for patients and health care providers who needed to ensure access to a limited supply of medications. Additionally,

some medications have adverse reactions, which could severely impair the judgment of combat warriors. Moreover, "none of the newer depression medications were even available to us" (interview).

Tricyclic Antidepressants

Discovered in the 1950s, tricyclic antidepressants have been used to treat mental depression. These psychotropic medications are named for their three-ring chemical structures. They work to correct chemical imbalances in the brain or to relieve symptoms of mental depression (Longe *Tricyclic Antidepressants* pp. 293–294). Additionally, tricyclics had been developed by this period, but "we just didn't use those much" (interview). Such psychotropic medications helped patients get necessary rest, especially when some could not even sleep at all.

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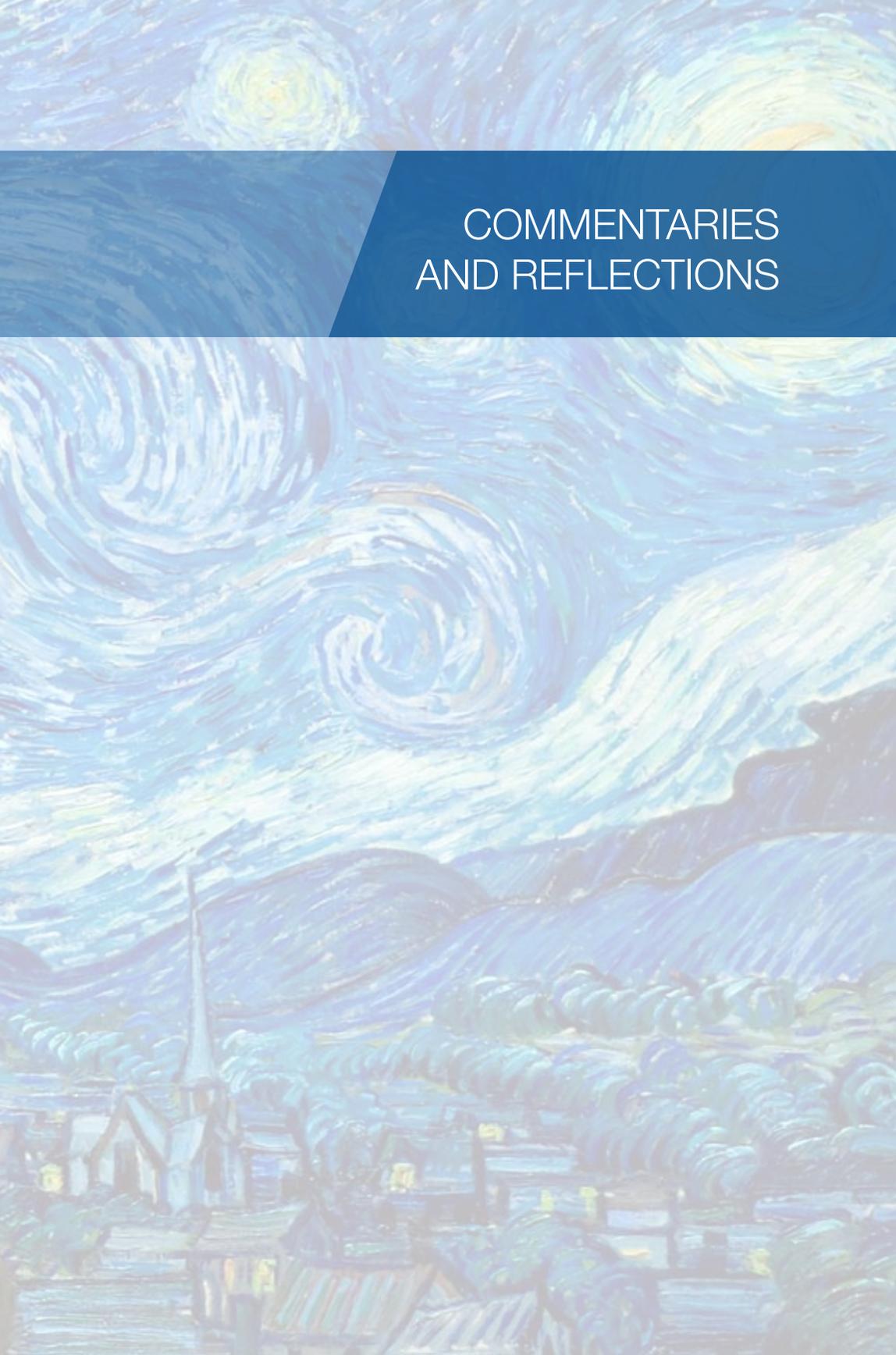
Finished with Training, Now What?
A New Scientist's Perspective

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What motivates one to become a scientist? After all, the average time to complete a doctorate in science and engineering related fields is approximately eleven years (Hoffer & Welch, 2006). When you add postdoctoral training to the mix, the most common path (Hoffer, Grigorian, & Hedberg, 2008), and a median annual salary of less than $100,000.00 (National Science Foundation, 2010), the appeal may diminish. Those that do decide to embark on this seemingly endless journey, do so out of passion with the hope of making a difference to their respective fields. Scientists are alike, no matter the field or location, in that they believe in an established systematic approach to generate and test hypotheses that ultimately leads to discoveries. Interestingly, upon completion of the necessary education and training an immediate discovery is made, which is possibly the most important of all. You really don't know everything as you may have envisioned and the path to becoming a great scientist is commitment, dedication and hard work.

As a new scientist, I have learned that no matter how remarkable the training was that you may have received, when you are on your own it is far from easy. Although advice from more seasoned scientists would unarguably be preferred, a young investigator's view may provide an invaluable description of what really awaits you. As a Naval research physiologist, it is my hope that this perspective will assist in transitioning from trainee to principal investigator, which is exciting yet quite intimidating. Of the many points that can be highlighted, I have learned that three of the most apparent challenges that exist include the selection of a mentor, searching and obtaining financial support and balancing administrative duties with research.

Throughout graduate school and/or training you begin to realize what qualities one should possess to be an effective mentor. This normally comes from both positive and negative experiences since not all scientists are good mentors. In being exposed to both, it becomes evident that a good mentor can guide your scientific development, whereas a bad mentor can make your life quite miserable. Although not all inclusive, most would agree that a mentor should be one that is approachable (even on bad days), available, dedicated, empathetic, fair, knowledgeable and, above all, a good teacher. In addition, a mentor should acknowledge your career path goals and assist you in reaching them, even if they are quite different from theirs. As these qualities and expectations may seem overly burdensome for a busy senior principal investigator, having more than one mentor can address this concern.

More specifically, there may be an experienced researcher who is a subject matter genius, however, another who may be more knowledgeable at balancing research with administration and navigating the system as a whole. Thus, it is difficult to argue that one would be a better mentor than the other and much could be learned from both. In speaking to other scientists, selecting and having a good mentor(s) may be the single most valuable asset a new investigator can have. In addition, it is important to distinguish between a good mentor and role model; although a role model may inspire a young scientist, a good mentor will effectively assist in the development of a good scientist. Moreover, just because a scientist has an astonishing record for obtaining funding and publishing, it does not necessarily follow that they are a good mentor. In fact, it maybe the precise opposite and your existence may merely be to help their careers. As such, being cognizant of this when interviewing and/or checking into your new position is highly encouraged.

As a postdoctoral fellow, research support is generally provided and the focus is on obtaining new laboratory skills, publishing manuscripts and assisting with preparing grants. In contrast, a staff scientist is expected to possess these skills and obtain funding—sooner rather than later—to support their research. In today's economy, it is not surprising that research dollars are becoming more difficult to acquire. The National Institutes of Health (NIH) proposed budget for 2012 is $32 billion (U. S. Department of Health and Human Services NIH, 2011). No one will argue that this is an enormous amount of money; however, what many do not know is that these dollars are unevenly spread across 218 research disease/category areas (U.S. Department of Health and Human Services NIH, 2010). In addition, the average age in obtaining a NIH RO1 grant is 42 and 44 years for those who have earned PhDs and MDs, respectively (Rockey, 2010); ages that do not normally coincide with "new investigator" status. More troubling is that if your research scope does not fall within NIH program announcements, which is generally the case for a Navy physiologist, the chances of securing NIH funding may not be in your favor. Alternatively, searching for grants through other agencies such as the Department of Defense (e.g., Defense Medical Research Development Program), Congress (e.g., Congressional Directed Medical Research Programs), military (e.g., Office of Naval Research) and the private sector (e.g., Howard Hughes Medical Institute) may be a better fit, thus increasing the likelihood of acquiring financial support. Although this is not intended to discourage new investigators, the probability in obtaining support as a new/early stage investigator alone, which the NIH defines as being within 10 years of completing a terminal degree or medical residency (Rockey, 2010), is not great.

An attractive solution to this bleak picture is to assume a co-investigative role and work with a more senior scientist. This may not be how you envisioned starting off as an independent researcher, but the reality is that writing fundable research proposals requires skill that may take years to acquire and is simply not just a matter of being a good writer with good hypotheses. Sharing your ideas and writing proposals with senior scientists not only increases the chances of being funded, but also helps your organization and reveals that you are a team player. Innovative ideas should be credited to those that generate them; however, it is my opinion that hoarding ideas that may never be pursued does not help science. Additionally, find out who the program sponsors are, contact them and introduce yourself and inform them of how your expertise can benefit the global picture. This may seem trivial, but a cordial introduction can paint a positive picture. Finally, remember that science is advanced by creative thinking and no matter how young one is a good idea is a good idea and should be pursed.

The last challenge that exists regardless of your status—a newly appointed assistant professor, research associate or military researcher—is balancing administrative obligations with research. There may be days that you are not working on research projects and will begin to reflect upon the previous 10 plus years of education and training only to realize that these tasks are unfamiliar. This can be frustrating. Although I have no solution to this lingering challenge, time management is essential to being a productive scientist. More specifically, use each minute of the work day to the fullest. Find time to read journal articles and search for funding postings and plan your schedule by the day, week, month, quarter and year. Do not become disgruntled if your schedule changes as this will likely occur regularly and being flexible is a must. I have always believed that there is never enough time in the day, yet there is always enough time to do nothing. It is during the "to do nothing" times that much can be accomplished and I believe that this can help you become a successful scientist. If administration is completely foreign to you, ask questions and choose mentors to help fill this knowledge/experience gap. Finally, remain optimistic as few will get the chance to make a contribution, a difference.

Transitioning from student/trainee to a fully trained researcher can be overwhelming. Selecting a good mentor(s) can ease this transition and is instrumental for the growth and development of a young scientist. Obtaining financial support to support research is difficult; however, working with senior investigators and writing grant proposals under their supervision, in a co-investigative role, improves the likelihood of securing grants. In addition, building on your successes as a co-investigator may lead to independent achievement over time. Finally, balancing administrative duties/obligations with research is a challenge that can be accomplished with good time management and optimism. Being a new scientist is not easy; however, hard work and dedication can dictate whether it is a successful experience. Although I am a young military scientist with much to learn, I am hopeful that my perspective will assist others who have decided to enter into the research race.

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Adoption: Identity Formation and the Transformation of the American Family

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Author Note

Abstract

Based on research on adoptions and evolving American definitions of the family, this study explores changes in cultural concepts and new forms of social identity. The research surveys scholarly findings and presents narratives of adoptive parents to offer relevant perspectives on the changing concept of "family". This article discusses community and societal responses to adoption and the extent to which parents and children in modern U.S. American families feel marginalized or accepted as equals to more "traditional" families. Questions of identity and parenting, what it means to be a parent and feelings of connectedness are discussed. The paper takes an anthropological approach by translating the perspectives of adoptive families as collected through participant-observation research and interviews, using narrative analysis, thereby lending these families a voice in a world that is otherwise influenced more by mass media and stereotypes rather than personal experiences, interpretations and interactions. Finally, the paper proposes ways in which healthcare professionals can better manage their adopted patients given the insight that the author has provided.

Keywords: Adoption, definition of family, culture, narrative, anthropology, social identity formation, healthcare.

Commentaries and Reflections

Introduction

We, in the United States, are in the midst of developing and changing our shared cultural understandings of what it means to be in relationship, how we define marriage, and ultimately what it means to be family. Among U.S. military professionals this trend in redefinition is also leading to an understandable re-consideration of some institutional cultural values and infrastructure.

Traditionally, the definition of family was based on blood relations. Adoption was considered a less favorable way of building a family and families tended to keep the adoption a secret or a taboo, not to be discussed. If a child was discovered by peers, their families or the administration to be adopted, she might experience stigmatization and marginalization in schools and communities. Mothers who chose to adopt were also stigmatized as somehow less than women who gave birth to their own children. In 1964, the sociologist H. David Kirk described the adoptive mother as "deficient" saying that both the biological structure of woman as child bearer and the social expectations of her "make her intensely role handicapped" when she cannot bear children (Kirk 1964: 129).

To this day, women might feel that they are somewhat "lesser" in their role of womanhood if they are unable to conceive and thus resort to adoption as the next best option to having their own biological child. Men, on the other hand, struggle with the thought of not continuing their male line, a concern that has not been scientifically linked to women's concerns. It is for such reasons that infertile couples will go through great lengths to find help in producing a biological offspring, rather than consider adopting first. In vitro fertilization is one alternative, but is expensive, and often unsuccessful. Surrogacy is another option that is expensive but at least ensures the offspring will have the husband's genes. It is at this point that healthcare professionals could interface with couples and discuss the benefits and risks involved in adoption versus various means of conception. Education is perhaps the first step in working through personal stigmas and assumptions.

After generations of stigmatization, and while adoption still is seen by some as a less than ideal means of creating a family, there is a societal change underway. Adoption has come into vogue as celebrities across the ideological landscape embrace adoption as a solution for the foster care crisis, as an alternative to abortion, or as a strategy for family formation and/or augmentation. Madonna, Michelle Pfeiffer, Sandra Bullock, and Angelina Jolie and Brad Pitt, to mention only a few celebrities, proudly announced the arrival of their adopted children (Pertman 1998: A1.) From hiding adoption in the mid 20th century to celebrating it in the 21st, acceptance of the American adoptive family is changing.

David Liederman (Pertman in Mandell, 2009), the executive director of the Child Welfare League of America, is quoted in numerous publications as having said, "Adoption as a lifestyle, almost unnoticed by everyone outside the field, is becoming as American as apple pie." The greater acceptance of adoption is indicated by the fact that family leave policies include adoption as well as giving birth and the federal government gives child care tax credits to adoptive families. Increasingly, corporations are providing workers with adoption aid, ranging from paid leave to large cash payments (ibid.)

Until recently, statistics on the number of adoptions were unreliable, due to the fact that the process was so private. As adoption has become more routine and transparent, experts are concluding that it is far more prevalent than they had thought. The Census Bureau did not ask about adoption until 2000, when they found that 2,058,915 adopted children are in U.S. households. There is no nuanced data on the types of households in terms of age or blood relations. The number of adoptees who are heads of household was not counted (ibid.)

Despite the reformulation of attitudes toward adoption, the idea lingers that one's biological children are preferable to adopted children. Elizabeth Bartholet, a Harvard law professor and an advocate of adoption, maintains that adoption is seen as a last-resort parenting choice, one that is inferior to biologic parenting: "This reinforces for the infertile the message that 'true women' get pregnant and give birth. A more positive construction of adoption would help free the infertile from the obsession to restore their sense of personhood by obtaining a medical fix" (Bartholet, 1994, p. 8 in Mandell). Healthcare professionals are instrumental in getting this message across.

The stigmas surrounding adoption are societal, not familial. Within a nuclear family adoption quickly becomes accepted as a fact of life. In one study (Benson 1994), most adolescents were found to have positive feelings about adoption and only 27 percent report that adoption "is a big part of how I think about myself." Overall, the study found that adoption does not typically complicate the period of adolescence. According to Benson, this finding contradicts the traditional perceptions of adopted children. He questions the disparity and explains it as a function of the samples: "The classical view is based to a considerable extent on clinical samples and a wider spectrum of adoptions, including those that occur after infancy. When the focus is on agency-assisted infant adoptions, the journey through adolescence appears to be, on average, less stormy" (ibid.)

In validating adoptive families as "real," it is also necessary to note recent health and psychological studies that affirm success of adoptive children in the family and, later, society. This begins with the ability of children to bond emotionally with family members since such bonds between child and parent(s) are a crucial factor in child and adolescent psychological development and later integration into society. One such study found that even though there is a concern that adoption might interfere with the attachment process, the results pointed to significantly high rates of strong attachment to adoptive parents.

> Adopted adolescents are as deeply attached to parents as are their non-adopted siblings. Fifty-four percent are strongly attached to both parents; 30 percent are deeply attached to one parent; and only 16 percent are not strongly attached to either parent. Equally compelling is the high percentage (95%) of parents who say they experience strong attachment to their adopted child. The vast majority of adoptive families, then, master a crucial process important to healthy development (Benson 1994).

Benson finds that one of the most salient characteristics of adoptive families in his study is the high rate of family stability and healthy social development. Only 11 percent

of adolescents report divorce or separation compared to 28 percent in a national sample of adolescents. He explains: "This may be due, in part, to the pre-adoption screening process typically employed by agencies during the 1970s. Adoptive families in this study typically evidence a high level of strength in terms of warmth, communication, discipline, and cohesion. Less functional parenting styles, such as authoritarian decision-making, are rare." The experience of the adoptive parent strongly counters the prejudiced notion of those choosing not to adopt, which includes the notion that bonds between adoptive parents and their adopted children are less strong and thus inferior to pure biological ties or indicative of future family breakups. Again, educating future parents on these scientific findings in the health sciences is essential in allowing couples to make decisions based on facts rather than hearsay. Mandell writes:

> It is heartening to see the stigma of adoption lessening. It is time to put aside the idealization of the biological nuclear family. Families take many shapes besides that one—adoptive families, gays and lesbians, childless couples, single women and men, step parents, grandparents and other relatives, older people. Adoption helps people to break away from the obsession with biological reproduction and ethnic purity and to embrace the "other." Open adoption could even pave the way to that ideal society for children where children could choose whom they want to live with, as in the Samoa described by Margaret Mead…. (Mandell 2009)

Idealistic portrayals of an evolving notion of the American family may seem impossible, but in fact the ingredients to what makes a family are changing and secrecy due to fear of stigmatization around adoption is fading in the United States. Nevertheless, hurdles such as social marginalization, whether real or at times perceived, remain.

Following is an attempt to explore some of these perceptions and realities of marginalization as told by the adoptive families themselves. Psychological and sociological studies point to stereotypes of the adoptive family as based on societal misconceptions rather than on the narratives of the adoptive families and the evidence of scientific studies. These stereotypes affect the future of adoptive families in both positive and negative ways, leading to a variety of narratives which support, refute and contest assumptions. They influence identity formation among American adoptive and traditional families. Stereotyping represents misinformation, hindering positive communication and identity formation. They represent perceived identities which affect our understanding not only of adoptive families, but of our beliefs about what makes a family. Over time, what should shape the concept of the American family are the personal narratives themselves.

Personal Stories

To understand better the development of the adoptive families' identities as compared to that of the more traditional American family, it is important that we listen to the words of the families themselves. We, in America, are in a period of transition with regards to what constitutes a family. The best way to understand the form it takes and the complexity of what it means to be a family in America today is to look at diverse histories and personal narratives.

Methodology

With this premise, and after having received necessary IRB approvals, I spent the past three years listening to the stories of twelve adoptive families and present two in this paper. The narratives are illustrative and composite in nature, drawn from a body of research. I have chosen these narratives for both their similarities and differences that yield insight into realities that, years ago, may not have been readily accepted in mainstream society and which, even in contemporary American society, are challenged in their acceptance as equals to biologically connected families. In finalizing the write-up of the narratives, I turned to the following questions from the interviews:

Questions:

1. Describe your family: the people, ages, what is important to know about them?
2. What names would you like me to use for you and your family?
3. How did you come to adopt?
4. When did you first see the child you were going to adopt and what was it like?
5. Please describe your child/children.
6. What were some of the good/great moments and some of the difficult moments since adoption?
7. Have you encountered any hurdles in feeling like a close family?
8. Have others been accepting of your family and how do they show it or not?
9. Has government or medical policy affected you either positively or negatively?
10. Is society critical of you for having chosen to adopt? If so, please elaborate.

The interviews were not all conducted in one session. Although some were by chance encounter, they evolved over time. I took notes in a journal and kept a record of emails. Once written, I sent the narratives to the families for approval, to ensure that I did not distort anything they had said. My results were positive in that no family had any changes to make. The following is a sampling of two stories:

Narrative 1

Marina was adopted by Amy and Frank Collert when she was eighteen months old. According to Amy and Frank, "it was the best of times and it was the worst of times." They had tried to conceive for years and finally came to the conclusion that they were destined to adopt, that "this is what God wanted" for them. They chose Russia as they wanted the baby to look like them, i.e. white. They wanted a younger child, and did not find any infants easily available through the American system. They also wanted to "rescue" or to help a child in need, but did not want the problems that might come from knowing the biological parents and felt that a baby from a foreign country would avoid problems that might come from the possibility of contact with the biological parents. They did not want a relationship with the biological parents.

As soon as the agency sent them some photographs and a short video of Marina, they knew it was meant to be. Her big blue eyes seemed to say, according to Amy and Frank,

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"I am yours. I have always been yours. You were just supposed to find me. Come and get me out of this misery." Their hearts hurt as they knew the process might take time, but they were determined now that they knew their daughter was waiting on the other side of the ocean. They were not going to give up. Amy explains: "I knew she was my baby. It is hard to explain to someone who has never had this experience, but it was like she WAS my blood. Certainly crafted somehow from my soul and we needed to be reunited. It was destiny, fate, call it what you like. I felt like she was lost and had been found. I needed to bring her home." And so began the journey that Amy and Frank call the best and the worst of times. On the one hand they had found their child, yet on the other, they could not bring her home immediately.

Beyond the immediate family who seemed to embrace the adoption, Amy and Frank had a strong church community that supported them in the process through prayer. Still, while Amy felt thankful to the strong community, Frank was more concerned: "I know they all supported the saving of a child kind of idea and the fact that finally we would have a child, but I felt that many just took pity on us. It was like they were supporting us because they felt sorry for us since we could not have our own. As if we were somehow not as healthy as they were, not as fortunate, not biologically capable and perhaps not their equals. This was different from the way Amy and I saw it. We thought we had been chosen, lucky and therefore special. I just felt others didn't see it our way."

Perhaps because of this perception of being seen as less adequate, Frank did not speak much about the adoption to others. Amy, on the other hand, became more proactive in finding people to support her: psychologists, Russian speakers, educators and the like. By their first trip to Russia, Amy was completely prepared and Frank allowed her to take the lead on decisions of packing and arranging the home for their child.

Upon meeting Marina, they were convinced that the match was real. Marina was not afraid of them, scrambled onto Amy's lap, laughed as Frank showed her her new doll. According to Amy: "It was as if the family had been reunited rather than united." Alas, the Russian system demanded that they leave the first time without their daughter as final official documents were put in order. For the parents this was excruciatingly painful. Amy: "Can you imagine leaving your baby behind in an orphanage in Russia? Ok, I mean, it was clean, and the people seemed to care about her. But who was going to tuck her in at night and pick her up when she fell. Some other woman? Not her mother? I could barely be coaxed to leave." Again Amy and Frank turned to the church for support through love and prayer. Again Frank felt the pity of others.

Narrative 2

Lucy always wanted to have children but was unable to do so physically. Her ex-husband did not want to adopt, so they broke up and Lucy, at 43, went ahead with the process. Lucy loves children and knew she wanted at least one. She considered the option to pay for egg and sperm donors, but she thought, "Why go through with that for a baby that technically wouldn't be mine biologically when I can save a child that was already born and needs a home?" Had Lucy been able to have her own, she probably would never have considered adoption; but, after the process and into today, feels "I wish people would adopt because now that I have seen what is out there, I wish I could adopt more children!"

While Lucy has no family living nearby, she is close to her mother and stepfather and does have other relatives including her three siblings and a father who is also remarried. Throughout the process and since adopting, Lucy did not encounter anyone who was not accepting. Lucy recounts: "My family and friends have been very supportive. Everyone treats her and talks about her as if she were my biological daughter. Everyone has kind words. Whenever I tell the story of her adoption, people are quite fascinated and supportive." Even strangers are generally supportive. The only sign that American society feels a woman is better off having her own are comments Lucy has received such as: " why did you choose to adopt" followed by "are you sure you can't get pregnant? Have you tried infertility drugs?" Lucy adds: "That's really annoying. I don't know exactly what their intentions are."

When Lucy first learned that a match had been made, she could barely look. She invited a friend to help support her: "The adoption agency called me and said they had a match and would email me a picture. I was really nervous and stared at my email waiting for it! When I opened the email, I had a friend with me, and I was soooo nervous. I didn't know how I would react. Would I love this child? Would it be immediate? I was really happy when I saw her. She is so cute! I was immediately in love. I started crying because it was finally really happening." From that point on, there was no question: Lucy and Sarah (age 3.5 at adoption) were meant to be together.

However, when it comes to the government support programs, she realizes that biological and adoptive parents are not treated equally: "I am upset that the government does not provide maternity leave for adoptive parents. I only have 5 weeks with her, which is from vacation time I saved, and I hope that's enough. Also, the government supposedly provides bonds for adopting, but the highest one I could find was $7500 and only goes to a few people. This makes it difficult for more people to adopt."

When asked to talk about the positive aspects and the aspects that are less than positive, Lucy explains:

> The best part of having Sarah is simply having her around and having a child! We have so much fun playing together. I love taking her to the pool, the park, the store, playing with her, throwing her around. It's so rewarding and such a wonderful feeling. It's also an amazing feeling to know that I saved her from a horrible life. The difficult things are: the language barrier—it is really difficult to communicate. The basics work, like eat, drink and sleep. But all day she tries to tell me things and when I don't understand her, she gets frustrated and I feel really bad. It's also hard to explain things to her. For instance, she's running around the grass and when she runs into the street I yell NO and she is so confused as to what I'm saying NO to and why I'm yelling at her. It's also hard when she is trying to figure something out, like a new toy, and I can't explain it to her. This also makes it difficult to figure out what's wrong, which is another difficulty. She is generally happy, but she has been having minor tantrums over almost nothing, and I can't discuss it with her. Also, she's been frightened of people and going out, which makes me feel bad, although we are making small strides. Also, she does not like TV or music, and she will not play with toys because she does not acknowledge them as her own

because she was trained that way in the orphanage. So it gets tough for me to physically play with her all day every day (although I love it, it gets challenging!)… What made this whole process easier is that she took to me right away. I feel we have a great bond. We always hug and kiss and hold hands, and she always hangs onto me and comes to me. The only thing is that she doesn't respond when I say "I love you" but I'm hoping that will come soon.

Discussion

In this study, findings on adoptive family identity formation and family members' sense of integration into the larger U.S. society is analyzed via the narratives they create and narratives supplied to them in various communities and contexts. Diversity in adoptive family narratives in U.S. society today helps develop the changing perspectives on the definition of the family. Some narratives outside the adoptive family hinder the general ease with which the adoptive family feels it can develop as a unit and ultimately be integrated into society. Other narratives, such as those within the adoptive family community itself, enable the development of strong adoptive families. Finally, individual adoptive families contribute to the acceptance of their model of family both within their family and to outsiders by creating their own unique narratives and myths.

From a social perspective, narratives are created by such institutions as religious communities, government and the medical system, to mention a few. In our first personal story, it is clear that the church community had a strong influence on identity formation and a feeling of acceptance of the Collert family. Frank in particular was worried that the community was accepting of his new family more out of pity than out of rejoicing at the uniting of members that were always meant to be together, the latter being a narrative he and his wife believe. While the Collert family experienced no open marginalization, Frank never could rid himself of the subtle feeling that his family was seen simply not the same as others. It made his desire to reach out for support less strong than his wife, who did not have the same feeling.

Other families interviewed expressed the feeling that while friends and community members superficially embrace their friends' adoptions, even within a family there remains doubts as to the possibility that the adoptive child will successfully integrate. One father secretly worried over the fact that his adopted child was given up for a reason by another family, for example.

While adoptive families often feel welcome in their smaller community, they still have hurdles to confront in larger society. As another adoptive family tells,

We have managed to dance around the "baby picture" and genetic science topics that come up in elementary and primary school, but probably they will come up. (The graduating yearbook usually contains baby pictures. Our earliest photo of her is from age 5.) Still, it is much easier to be adopted in the US now and lots of books and TV shows aimed for her age address it pretty well. It helps that she has three friends who are adopted… (Karen, 2011).

The education system is yet another area that has not become completely acclimated to the new American Family.

Other narratives which affect the creation of adoptive families include assumptions of race and the importance of keeping race and appearance in the family the same. Like many adoptive families interviewed, Amy and Frank wanted to adopt from Russia because it was one place they could find a white baby to match their race. This desire to equate what is natural in the context of a biological family as "normal" and desirable in the context of adoption is part of a the natural myth (see Bartholet 1994: 4). Similar narratives are created on the subject of class and same sex or gay parents. The fear remains that racial dissimilarity would exacerbate the already unnaturalness of their family via adoption.

There is a perception among the families that the medical system also marginalizes adoptive families by making medical assistance difficult to navigate and expensive, thereby affirming the myth that giving birth is the "healthy" or "natural" way. Those who cannot give birth are seen as possibly damaged or somehow lesser. Bartholet writes that there is a myth in American society that is rarely openly admitted, but still affirms that "true women get pregnant and give birth." (Bartholet, 1994 in Mandell). The healthcare profession has the potential of becoming an asset rather than a barrier to successful adoptive families via education of the families and outreach to communities.

While outside the adoptive families narratives contest the naturalness and potential for positive development, inside the adoptive family narratives tend to explore naturalness of adoption. For example, adoptive parents tell stories to their children to make sense of their differences from the "traditional" families surrounding them and to explore new traditions and rituals that reinforce their bonds. As one adoptive parent writes "Since becoming a parent 14 years ago, I've come to feel that the process of family creation combines the randomness of a Lotto drawing with the painstaking construction and maintenance of a whole small world of rituals, values, quirks and mythologies." (Phillips 2005). Narratives from the parents include, for instance, those about how families "found" or "were led to" a child; how the adoption was "meant to be;" and how a mother immediately feels a natural connection to the child upon the first viewing on the internet.

Conclusion

This article takes as its starting point the notion that research based on personal stories are critical to understanding cultural change. These narratives can be the force behind building acceptance of new social relations and understanding an insider's perspective, an essential component to developing empathy and creating new common understandings. Healthcare professionals are encouraged to learn more about the potential for outreach in educating couples and entire communities on the realities of various kinds of family building and specifically on the risks of medical procedures, concerns about adoption and the potential for success in each case. Communication via narratives, be they written, grass-roots media, spoken or otherwise conveyed (as through art or brochures for example) represents the springboard from which to launch discussion; and enhance "intra"-cultural communication and, hopefully, a deeper acceptance of diversity that will be reflected beyond the community level into education and public policy.

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Interviews

Amy and Frank Collert (pseudonym), September–November, 2010.

Lucy (pseudonym), summer 2011.

Karen (pseudonym), September 2011.

The End of Modern Medicine: The Evolution of Disease and Transformations in Medical Practice

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Abstract

This article explores the notion of what may be considered a growing disconnect between the epidemiology of disease and the structure of contemporary medical practice. The rising prominence of chronic illness, along with problems ranging from healthcare policy and delivery to diagnostic and treatment processes, is well documented. The purpose of this article is to connect these various dialogues to what seems to be a broader underlying shift in the landscape of contemporary health and medicine. Historically, medical perspectives and institutional structures evolved to match the causal model of infectious disease, with astounding success. We posit that the shifting complexities of chronic illness are effecting a shift in the nature of contemporary health relative to the practice of medicine that helps frame a spectrum of problems now facing the profession. Of particular importance is the need to explore emerging new horizons for the practice of healthcare in the future.

Keywords: chronic illness, epidemiological transition, modernity, social causes of disease

Commentaries and Reflections

Introduction

Modern medicine's accomplishments since the discovery of bacteria are literally awe-inspiring. In recent decades, most agree that the profession has not only grown increasingly complex and difficult to navigate, but that a variety of changes are needed. In a recent address to the graduating class at Harvard Medical School, Gawande (2011) contrasted the current use of multidisciplinary medical teams, whom he likened to "pit crews," with the classic solo practitioner, whom he likened to a lone "cowboy." Similarly, from every direction, we see calls for change in primary care, reimbursement, and education, among other areas. However, many comments on the challenges facing contemporary medicine often reflect, consciously or unconsciously, an idiosyncratic vision of how the field is changing. They imply, though often tacitly, that the problems with interdisciplinary teamwork addressed in one venue are distinct and can be approached separately from problems of medical education, clinical practice, and the like.

This article explores the concept that the transformations in multiple fields related to medical practice and healthcare delivery emerge from a common deeper shift in the landscape of contemporary health itself, one that seems to be signaling the end of the traditional medical paradigm and the beginning of newly emerging and uncharted horizons. Certainly, this is not to suggest the literal end of medicine itself, but rather that new complexities in health and healthcare necessitate paradigmatic transformations in medicine. That is, underlying changes in the health landscape require medicine to reinvent itself fundamentally, as it did once before, after the discovery of bacteria. While the specific indicators of this shift have been variously discussed in the literature, we illustrate the common underlying cause for an array of challenges facing medicine that often are viewed idiosyncratically. Moreover, what is discussed is representative of common challenges presented by a more general shift away from the modernist foundations of the industrial society that attend the development of most social institutions, including medicine and healthcare. While such transformations in health and medicine affect every area of the expansive institutional network that supports healthcare delivery, we will focus in this article largely on physicians and clinical practices, because healthcare is still delivered primarily by physicians in clinical settings. This focus is therefore most clearly illustrative of the growing challenges in the relationship between the modern medical paradigm and contemporary health.

Critiques of the biomedical model have existed as long as modern medicine itself, but disease patterns and therapeutic successes made these easy, if not legitimate, to minimize. Today, however, it is not only disciplinary interest from the social sciences and the humanities, but the physiology and epidemiology of disease itself that underscore the limitations of traditional biomedicine (Wasserman & Hinote, 2011). These changes reflect not simply a maturing of twentieth-century medicine, but a call for a fundamentally revised medical paradigm (Kuhn, 1962), where definitions of health, domains of practice, and professional boundaries all must be reconsidered. Failure to do so promotes a time-bound vision of the contemporary challenges facing medicine as though they exist independently from each other. This raises the possibility of responses that are neither complete nor cohesive.

This article will first discuss the changing landscape of health and illness, most notably the ways that epidemiological transitions have reconfigured the kinds of phenomena

that should be accounted for in the practice of medicine. Notably, this includes the sharply increasing salience of social factors. We will then characterize the nature of modern medicine, including its ontological vision of disease causation and treatment, as something developed alongside interventions for infectious disease. We will conclude by showing that the foundation of modern medical practice and the various institutions built upon it may be posited as fundamentally mismatched with the most pressing contemporary epidemiological challenges. This disconnect will be briefly explored in several core areas, including where care is delivered and how labor is divided, professional satisfaction and reimbursement, and medical education.

It may seem odd to suggest that modern medicine, the success of which clearly continues today, is coming to an end. Of course, doctoring itself, as a greatly needed profession, certainly is not ending, but the modernist paradigm in which it found its early success and prestige may now be giving way to new formulations of medicine and health. Moreover, its success is precisely what has given rise to the challenges it now faces. Medicine's accomplishments in treating infectious disease, both in the clinic and through public health measures,1 initiated the epidemiological transition, where chronic illnesses became the primary mortality threats in developed countries, mainly due to increased life expectancy (Cockerham, 2007). The impact of this shift has been central to broadly scoped public health programs, but its significance for medical practice itself remains seriously understated. This is especially problematic because the profiles of chronic and infectious disease are paradigmatically different. Therefore the modern conception of medicine, which is matched so well with infectious disease, likely will increasingly fall short as chronic illnesses constitute a greater share of the epidemiological picture.

Chronic Illness and Epidemiological Complexity

Broadly speaking, the diagnostic process seeks to identify the cause of a given set of unwanted symptoms. For infectious disease, suitable causal models have historically centered on proximate pathogenic factors. Explorations into broader contexts like environment typically were limited to where a person contracted the infectious agent (e.g., the water they drank or their associations with other infected people). However, the etiology of chronic illness looks very different. The cause, progression, and outcome of those diseases significantly depend on "lifestyle" (Cockerham, 2007). While that term is pejoratively used in multiple public health and medical disciplines to indicate individual choices alone, in medical sociology it signifies the complex interplay of individual choices and social structural chances. In the chronic illness era, health—or disease—increasingly results from the dynamic interaction of hundreds of thousands of cumulative individual decisions, all of which are inextricably embedded in complex sets of social opportunities. Along with social and behavioral factors, there is an ambiguous contribution from genetics. Whereas most infectious diseases can be successfully diagnosed with universal scientific principles applicable to generalized bodies, the pathways of chronic disease are simultaneously related to individual behavior and conditioned by numerous social contexts, making them difficult to diagnose using those same archetypical causal models.

Commentaries and Reflections

The Social Causes of Health and Illness

Evidence of the influence of these multiple social contexts, and the measurable ways that they shape individual choices and even the expression of genetics, exists throughout the medical, social science, and even popular literature. For example, in recounting the mid-twentieth-century work of physician Stewart Wolf and sociologist John Bruhn, Malcolm Gladwell (2008) describes the seemingly exceptional city of Roseto, Pennsylvania—a town of Italian immigrants first settled in the 1880s. The "mystery" of Roseto was not a new infectious threat or developing chronic disorder. Rather, the baffling demographic trend in this small town was that its residents were dying of old age, not disease, at a time when heart attacks were the leading cause of death among men below age 65 in the United States. None of the typical explanations appeared to account for this phenomenon. These residents even smoked heavily, and many were obese; yet they somehow evaded widespread cardiovascular disorders at a rate that was one-third that of towns only a few miles away.

Eventually, Wolf and Bruhn realized that they would not find the essence of Roseto among the individual choices of its inhabitants or their DNA, but rather in how they visited and interacted with one another, their extended family structures, their highly integrated ethnic, civic, and religious ties, and the egalitarian nature of their community. In short, Wolf and Bruhn illustrated, very early on, that we cannot understand health by thinking about isolated individual choices or actions, but must look to a host of complex, seemingly "mysterious and magical" social forces as determinants of health and illness (Gladwell, 2008, p. 10). While medicine then was successful enough to avoid widespread adoption of a broader sociological perspective in medical practice, more recent research suggests this position has become less sustainable over the last several decades.

Bruce Link and Jo Phelan (1995, 2000) provide more evidence of social factors as critical determinants of health and disease. They note that while researchers achieved notable success in identifying risk factors for many major disorders, the majority of research focuses upon proximal (rather than distal) causes of disease, many of which disregard social factors, resulting in hyper-individualistic notions of health and illness. Link and Phelan (1995) call these frameworks into question and argue that researchers and practitioners must devote significant attention to social factors as "fundamental causes" of disease to maximize the effects of health interventions (i.e., healthcare policy, delivery, and practice). They offer two justifications. First, individual-level risk factors must be contextualized by identifying exactly *what* puts individuals at risk of disease (i.e., at risk for risk factors). Second, social factors are "fundamental causes" of disease that "embody access to important resources, affect multiple disease outcomes through multiple mechanisms, and consequently maintain an association with disease even when intervening mechanisms change" (1995, p. 80). The fundamental cause explanation derives support from studies examining multiple risk factors and many diseases (e.g., Link & Phelan, 2000; Phelan, Link, Diez-Roux, Kawachi, & Levin, 2004).

Link (2008, p. 367) more recently explains that, "When biomedical knowledge and technology create the capacity for humans to avoid disease and circumvent early death, sociological factors become more . . . important for population health." Put another way, where the modern biomedical model has helped us conquer the epidemiological threats of

one time and place, social contexts assume a new significance in shaping health outcomes in the next era. Advances in deciphering the origins and pathways of disease manifest new and more complex ambiguities surrounding novel and increasingly complex pathogeneses.

New Complexities in Health and Disease

Conceptualizing health and sickness in a manner that accounts for the complexity of chronic illness helps emphasize the ways that the contemporary epidemiology of disease is increasingly incompatible with approaches that embrace the modernist causal model of health. Sociological researchers report that those causal models are incompatible precisely because they do not adequately account for many of the social and structural contexts (e.g. Link & Phelan, 2000) that are critical in promoting health and well being, particularly for chronic illnesses. Even survivability after disease onset is closely associated with these same contexts (Cockerham, 2007; Scott, 2005).

Although this article mainly addresses the ascendancy of chronic illness and consequent social transformations in medicine, acute illness trends merit brief comment, as these also reflect a fundamental shift toward complexity that requires rethinking the archetypical causal model. Early successes treating bacterial and fungal infections gave rise, epidemiologically, to viral infections and cancers with more complex pathogeneses. Moreover, successes treating viruses produced even more complex multi-drug resistant strains. Cancers display complexity from their position at the juncture of acute and chronic disease, with currently unspecified contributions from lifestyle, genetics, and infection (American Institute for Cancer Research, 2001; Ellis, 2003; Goedert, 2000). The physiological structures of bacterial and fungal infections stand distinct from human systems, meaning they fit well with the modernist causal model, because they are discrete targets of treatment. Alternatively, modern medicine has had less success with the more complex etiologies of viruses and cancer. Every point on the spectrum of acute disease has undergone its own shift toward increasing etiological complexity, including bacteria and fungi (Scheld, Hammer, & Hughes, 2007). While complexity on the infectious frontiers necessitates fundamental shifts in the nature of medical science and practice, this is all the more true for chronic illnesses, which are now the most significant mortality threats in developed countries.

In modernity's wake, medicine must increasingly engage the social factors fundamental to the complex etiology of chronic diseases (as it must also, though perhaps in different ways, for emerging acute ailments with increasingly complex etiologies; Cockerham, 2007; Link & Phelan, 1995). While there have always been calls for physicians to be more sociologically aware (McIntire, 1894), the relative causal simplicity of many infectious diseases, which gave rise to modern medicine, produced little impetus to do so. However, since the profile of chronic illnesses fundamentally intersects social factors, it is ever more important to address these contexts within the diagnostic process (Link & Phelan, 1995). Most physicians recognize the social features of doctor-patient relationships, even if those social dimensions are limited to ad hoc bedside strategies. Today, however, novel manifestations of chronic disease necessitate greater, deliberate inclusion of sociological influences in the diagnostic and treatment process itself.

Commentaries and Reflections

Medicine Moving Forward

The seeming disconnect between modern medicine and contemporary health is increasingly evident. Whereas the magic bullet hopes of the early twentieth century were extreme even then, penicillin and other antibiotics nonetheless cured an entire spectrum of infections. Today, however, chronic illness treatments typically emphasize long-term symptom management. This clinical goal reflects the mismatch between an old, causal model and the profile of new kinds of illness. Since the etiology of chronic illness often is too complex to intervene in the path between the body and disease itself (as with vaccination, antisepsis, and other treatments that eradicate or prevent disease in the body), the modernist model is relegated to treatments attempting to disrupt the path between the disease and symptoms emanating from it. Despite being more technologically advanced than ever, medicine today arguably engages in increasingly more treating and proportionally less curing because the pathogenesis of chronic illness defies the causal perspective of disease that made medicine a curative practice and so successful.[2] In this section we will discuss how the paradigm of contemporary health consequently defies a variety of aspects of modern medical practice. These include the structure of the clinic, a highly specialized division of labor, reimbursement systems, and medical school curricula. These individual challenges facing medicine have been discussed before. However, the focus here is to illustrate that they are not idiosyncratic, and cannot be addressed in isolation from one another, but rather stem from the same core shift in the landscape of health. In turn, responsive changes in each must be conscious of and responsive to the core epidemiological transformations we have highlighted. We include considerations for framing changes in these areas.

The Locus of Treatment and Division of Labor

The clinic is the traditional, sustainable and preferable locus of patient treatment when dealing primarily with infectious disease. Yet when the fundamental causes of chronic illnesses are connected to the circumstances in which patients live, and the choices they make within those contexts, the disengagement of the clinic from the patient's environment poses substantive challenges and potential problems. (LoFaso, Breckman, Capello, Demopoulos, & Adelman, 2010). In clinical interactions, physicians may ask about health behaviors, but they do not always get complete information (Holtgraves, 2004). This is not as troubling with infectious disease, since tests can confirm syphilis, for example, over and against a patient's testimony. Certainly some chronic disorders are given discrete criteria, but these usually are constructed from designated points on a scale (such as levels of cholesterol or blood sugar), not the presence or absence of some thing itself (as with a virus or bacteria). Moreover, even when chronic disorders are discretely diagnosed, it is difficult to understand their causes or what patients are really doing day-to-day to manage them, because these ailments depend on numerous micro-events. Certainly tests such as the hemoglobin A1C—which gives a three-month weighted average of glycated hemoglobin and therefore a more longitudinal picture of blood sugar than the traditional blood glucose snapshot—can in some way document the veracity of patient reports about lifestyle behaviors. However, complexity pervades and confounds even where such tests are available. For the A1C test, hemoglobin glycation varies on the basis of many factors, including race and age (Bloomgarden, 2009). Moreover, the stable statistical correlation of glycogen to glucose within groups has limited explanatory power for any given individual.[3] The persistent common denominator for chronic illnesses is a complexity that requires incorporating a broader vision, where new conceptualizations of health and illness (social and behavioral among them) are central features of diagnosis and treatment.

Limitations in the structure of clinical practice and the treatment of chronic illness must be addressed with a variety of changes. A push for returns to home visits might be one step in the right direction because it gives the physician a better picture of the daily life of a patient. While by no means complete, as "presentation management" will still attend the doctor-patient interaction (Goffman, 1959), delivering care in the patient's routine environment nonetheless provides for a deeper sense of lifestyle (both social context and choices therein) to be ascertained. This is particularly promising in concert with the push to increase the number of physicians going into primary care and general practice, as these are areas of practice presumably most amenable to changes in the locus of treatment and that could most benefit from doing so, as they have more generalist scopes of practice. Physicians would do well to augment the locus of delivered care with diagnostic capacities that incorporate social and environmental information in the same way that somatic information is diagnostically utilized in the current clinical model. Adapting practice locations to provide this opportunity is an important first step.

Health Care Administration and Professional Satisfaction

Just as the structure of the clinic is matched to the modernist infectious disease model, so too is the administration of healthcare. Like other aspects of medical practice, the financial and regulatory systems in which physicians practice emerged from the modernist paradigm, and therefore also face new challenges in light of the shifting landscape of health. While the administrative and institutional expansion of healthcare delivery often is seen as a natural inclination of institutions toward growth (Weber, [1947]1997), this growth can also be understood as a function of the expanding complexity of health and disease. Put simply, a more complex phenomenon engenders a more complex system. At the same time, however, existing evidence documents declines in professional autonomy and satisfaction (Zuger, 2004). While physicians commonly cite increasingly cumbersome administrative demands, we might argue that the mechanics of daily professional life are only symptomatic of the deeper problem of epidemiological complexity. Reimbursement is one key area where clinical practice and health care administration directly intersect. Currently, the kinds of diagnostic and treatment practices for which a practitioner can be reimbursed center on acute interventions, while the causes of most diseases that threaten the lives of people in developed countries are non-acute (Berenson & Rich, 2010). We suggest that being obliged to practice in a way that is not responsive to the diseases patients increasingly face likely contributes significantly to professional dissatisfaction. The strictures and rigidity of bureaucracy often can be annoying, but the way in which the rules and procedures of modern medical bureaucracies contribute to the fissure between contemporary illness and medical practice may signal a deeper existential crisis within the practice of medicine—one that we believe is only beginning to materialize.

Calls to reform the reimbursement structure of medicine proliferate, but often without conscious recognition of the deeper shift in the overall health landscape. In noting that dominant proposals for reimbursement fall short of enhancing primary care, the central problematic lurking in Berenson and Rich (2010) deals largely with the mismatch between those systems and the complexity of chronic illness. For example, of episode-based and bundled payment proposals, they write, "While many of these chronic conditions cluster together, e.g., hypertension, congestive heart failure, diabetes, chronic renal failure, etc., current episode payment approaches (as well as clinical practice guidelines and P4P

measures) generally assume independence of these conditions" (Berenson & Rich, 2010, p. 617). While the authors' conclusion is to amalgamate the strengths of various systems, how these strengths should be determined remains unexplained. We suggest that the extent to which the features of a payment system can enable a physician to address the complexity of chronic conditions, in particular the inclusion of social and environmental determinants of disease in the diagnostic and treatment process, should guide that discourse.

Medical Education

Another area that sees calls for change is medical education. At the dawn of the twentieth century, the discovery of bacteria was quickly propelling medicine to new professional heights. Physicians finally had rigorous science on which to base their treatments, which had previously emerged from longstanding traditions, theories, and ad hoc bedside observations. Flexner's 1910 report on medical education in the United States was critical, if a little severe,4 in pushing medical curricula and university facilities to keep up with the scientific advances of the time (Duffy, 1996). In what is considered a sequel to Flexner's study, Cooke, Irby, and O'Brien (2010, p. 1) write that once again,

> Medical education in the United States is at a crossroads: those who teach medical students and residents must choose whether to continue in the direction established more than a hundred years ago or take a fundamentally different course, guided by contemporary innovation and new understanding about how people learn.

This article adds that a significant dimension of the challenges facing medical education emerges from the nature of contemporary health that requires physicians to be differently prepared. Cooke et al. (2010, p. 1) acknowledge something similar, writing, "New technologies and drugs are radically altering diagnostic and therapeutic options, and physicians are playing both broader and more specialized roles in an increasingly complex healthcare system." However, it is not only the infrastructures and institutions of medicine that have become more complex, but the profiles of the actual diseases medicine most commonly treats today.

While the body of literature calling for changes to medical education is too extensive to cover in this article, the underlying sensibility of many contemporary proposals for curricular reform centers on the growing complexity of the health landscape, though with varying degrees of consciously recognizing this broader foundation. A good example is Hodges (2010), who writes:

> Flexner's diagnosis in 1910 was a lack of scientific rigor, and his prescription was to strengthen the scientific basis of medical education. These new reports appear to focus more on physicians' lack of adaptability, flexibility, and alignment with social need. Their prescriptions rest more on changing educational contexts, the nature of teaching, and the process of professional socialization than on modifying any particular content area. (p. S35)

Related to this, Hodges (2010, S35) notes, "What strikes me . . . is the prominence of a dual imperative for defined outcome standards with a call for pedagogical models

that are individualized."5 With regard to our thesis here, the former imperative reflects a modernist drive for discrete, if not quantifiable, results. The latter suggests at least a tacit sense that, insofar as the contemporary picture of health and illness requires increasingly individualized care that is sensitive to social arrangements, a corresponding curricular framework must educate physicians in addressing these complex features of contemporary illness. Moreover, there appears to be a clear sense that medical school pedagogies must be individuated to match the complexity of contemporary health (Cooke et al., 2010; Hodges 2010). In the end, focus has been directed more toward the quality of education rather than on those sorts of epistemological considerations. Hodges (2010) for example, concludes that we ought not rush to abandon old models because of uncritical enthusiasm for new ones, but rather should address thoughtfully how to synthesize a variety of educational approaches in medicine. However, just what curricular aims and methods ought to be brought together in this synthesis requires integrating those best aligned with the shifting health landscape.

Conclusion

Of course, medicine itself is not coming to an end. The acute diseases and injuries upon which modern medicine was built still exist, and new and challenging versions are emerging. To be sure, we must celebrate every therapeutic breakthrough. Still, every advance in curing acute illness increases the proportional significance of chronic disease and fuels the need for a responsive transition from medicine.6 We see calls for more general practitioners, for more engagement with the social psychology of patients, and the behavioral contributions to illness. Such calls can echo the past. Therefore, it can be easy to overlook the heightened importance of these calls in contemporary health. To effect significant improvement in chronic illness, the modernist causal model of disease must be incorporated into a new paradigm with a broader vision of health, disease, and medical practice. However, without awareness of the central underlying shift toward complexity, for which the modernist approach appears to have limited utility, we will likely see piecemeal solutions to an array of challenges and continued attempts to rearrange the surface of existing systems without addressing the fundamentals of the status quo. In turn, we may likely witness a growing disfranchisement of both practitioners disillusioned with the profession and patients who increasingly seek health advice from non-professionals (Hartzband & Groopman, 2010). Our goal in this article has been to illustrate that, insofar as they were constructed around infectious disease, it is precisely the fundamentals of the status quo that need to be challenged to confront that dramatically changing epidemiological picture of health.

Medicine has yet to realize an appropriately responsive engagement with the etiological complexity of chronic disease. However, we can see individual calls for reform in clinical practice, medical education, healthcare administration, and any number of other areas. We hoped in this article to elucidate how what sometimes appear to be idiosyncratic proposals have the same underlying basis. Successful revision requires being conscious of that underlying picture of health to which individual efforts ultimately are aimed. A larger coordination of those efforts can only be promoted through recognition of that common basis. All of these efforts, after all, will ultimately be judged on how well they affect patient care, and whether they constrain or enable a medical practice that is matched with contemporary health and illness.

The diagnostic process is central to medical practice, and today, when social factors are fundamental causes of disease (Link & Phelan, 1995), the practice of medicine requires acuity of social behaviors and environments. It has always been important to improve the social dynamics of patient care, but the sociology of health and medicine was somewhat peripheral to actual medical practice when it was so successful at curing disease with purely biomedical principles. However, sociological awareness in medicine is no longer primarily about making patients more comfortable or pleased with clinical interactions. Because of the nature of health and disease, the sociology of medical practice now fundamentally engages the areas of diagnosis and treatment. In the era of chronic illness, there is a complex web of multidimensional causality confronting healthcare delivery and medical practice that requires a profound shift toward humanistic engagement.

Notes

1. While today public health is something of a distinct field, we ought not forget that physicians and nurses led the way for most of the twentieth century, using their medical knowledge at the community level, and that they remain heavily involved today, both in the production of public health knowledge and its practice. Indeed, the ascendancy of public health as a distinct field, with distinct methods and foci, evidences the fracture in the health landscape that we discuss here.

2. In fact, even though it is used more generally today, the term "pathogenesis," with its root word being "pathogen" and first used in 1876 after the discovery of the germ, reflects the dominance of infectious disease in the development of modern medicine.

3. That is, the average individual deviation from the mean is significant enough to raise concerns about error in assuming this test gives a window into individual, rather than group, behavior (something known as the reductionist fallacy). Citing a study by Wilson and Kollman, Bloomgarden (2009, p. e143) writes, "analysis of a pediatric population showed that while there was a strong correlation of A1C with mean glucose in the group, the use of A1C to estimate mean glucose in individuals would lead to error."

4. Flexner's report is often considered, with some reason, to have been problematic in that it led (in some cases to Flexner's own chagrin) to the closing of many non-allopathic institutions, as well as all but two medical schools training African American physicians (Howard and Meharry; see Duffy, 1996).

5. Cooke et al. (2010) make the exact same point as one of their four key goals for medical education includes needing to, "Standardize learning outcomes and individualize learning processes."

6. Not to mention that many times these therapies yield more complex strains of a treated infection.

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Film Review:
Sisters of Selma—Bearing Witness for Change
A Co-Production of Hartfilms and Alabama Public Television
Producer-Director Jayasri Majumdar Hart (2007)

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Introduction

"A man dies when he refuses to stand up for justice," spoke Reverend Martin Luther King, Jr., to a standing room only audience on March 8, 1965, in Selma, Alabama. "A man dies when he refuses to take a stand for that which is true." The previous day, known ominously today as "Bloody Sunday," local and state law enforcement violently suppressed a group of approximately six hundred civil rights protesters as they attempted to march to the state capitol in Montgomery, Alabama. The goal of the march on that Sunday was to seek redress from then Governor George C. Wallace for political and social grievances, specifically the right to vote for African Americans in Dallas County, Alabama.

Just nine months before, in July 1964, citizens of the South and the U.S. at large watched as then President Lyndon B. Johnson signed into law the *Civil Rights Act of 1964*. The law mandated to all states the ending of segregation in public places and the ending of racially-based discrimination through unequal voter registration applications, among other monumental protections, for historically oppressed minority groups. The Act signaled a transformation in the United States, specifically in the deep South, where minorities and poor whites were routinely denied the right to vote due to overly burdensome qualification tests for voter registration. Examples of methods applied included poll taxes, literacy tests, and sometimes explicit threats and acts of violence on persons not deemed "qualified" to vote. In the Deep South, these persons were disproportionately African Americans.

Selma was the county seat of Dallas County, Alabama. Located on the Alabama River, it was also the state headquarters of the White Citizens' Council, a pro-segregationist organization at the time. In 1961, Dallas County's African American population represented fifty-seven percent of the total population, but accounted for less than two percent of the county's registered voters. Four out of every five African Americans lived under the poverty line.

Motivated by the lack of proportionality in voter registration and access to the electoral process, civil rights groups such as the Dallas County Voters League and the Student Non-Violent Coordinating Committee (SNCC) began to mobilize and organize African Americans in Dallas County for the purpose of voter registration. What began as a voter registration drive in the 1950's and early 1960's reached an apex in March 1965. After the

events of "Bloody Sunday" and the national organizing calls made by Reverend King, Jr., these organizations were joined by thousands of other Americans who were being made aware of the violent suppression through the popular utilization of television as a media source. Among those who responded to the calls for assistance and solidarity were members of the Catholic clergy and nuns, including the *Sisters of Selma*.

Film Summary

Sisters of Selma chronicles the overlapping stories of twelve Catholic sisters as they relive and expound on the most significant events of the civil rights movement in Selma, Alabama. The film centers on the experiences of the six sisters who were part of the very first march after the events of "Bloody Sunday." Complimented by interviews with a host of significant players in the movement and disturbing yet riveting archived footage, the sisters take us through almost a day by day recounting of the days and weeks following "Bloody Sunday" in the lead up to the final march on Montgomery. The initial six were Sisters of St. Joseph of Carondelet, Sisters of Loretto, and a Franciscan Sister of Mary. These women, along with a good number of Sisters of St. Joseph of Rochester serving in Selma already, risked everything, including their lives and professional servitude, to bear witness to the injustices being suffered by African Americans living in Selma and the surrounding areas in the early 1960's.

As the film begins, we are immediately offered a small glimpse into the motivating rationale for some of the joining nuns. "The Sisters of St. Joseph are willing to be risk-takers," stated Sister Ernest Marie, one of the first six nuns to respond to Dr. King's call to march on Selma. She makes an accurate assessment, as the Sisters of St. Joseph of Carondelet first arrived to the U.S. in 1836 as only a group of eight women with the mission to establish a school for the deaf. The St. Joseph Institute for the Deaf still operates today.

Of particular importance for younger viewers is to understand the differences in the lifestyle and images of Catholic religious sisters in the 1960's. Traditionally, sisters were often in the education or nursing ministries. Consistent with attitudes at that time, religious women were often backseat contributors to the common good. However, their presence and enduringly powerful religious ministries were the backbone of American Catholicism. Then in the 1960s, Pope John XXIII called the Second Vatican Council into being from 1962–1965. This was only the second Council in 400 years. Most importantly, this Council was the first time that the Roman Catholic Church did not face off defensively with the modern world. Of immense impact, the Church at this time welcomed modernity and the challenges it was bringing to human development and the call all persons of faith were to have as instruments of justice and peace. It is out of this context that one can understand the immense call and price that the Sisters of Selma endured then and into the following years.

Alston Fitts III, noted Selmian historian, sets the tone for Dallas County race relations in the 1960's, albeit a heartbreaking one. Dallas County "…was not a Ku Klux Klan County for the most part," states Fitts. However, he does note that racism was omnipresent at the time—the only difference was organizational and institutional tactics being utilized to implement the racism. As Fitts notes, the unofficial motto of the White Citizens' Council at the time was, "Why burn a cross when you can foreclose a mortgage?"

Even though the *Civil Rights Act* was signed into law in July of 1964, only a little over two percent of African Americans were registered to vote in Dallas County by that November. The voter registration process was still antiquated and designed to oppress voting-eligible African Americans in Selma. For example, voter registration education classes were held for white teachers before they went to formerly register to vote, but those classes were never offered to minority teachers. Additionally, when voter education and registration groups like SNCC and the Dallas County Voters League attempted to fill the void left by this intentional application of inequality, an Alabama state judge ruled that no one could organize publicly in groups of more than three people if the sponsor of such group was a civil rights organization. Thus, from that ruling on, it would now be a crime for African Americans to peacefully assemble in order to assert their civil rights.

After the injunction issued by State Judge James Hare forbidding public discussion and assembly, the Selma civil rights movement found itself at a critical juncture. Reinforcements for the front lines were needed to continue to educate in the shadows, but the movement also needed a reinjection of energy and hope from the top. Enter the Southern Christian Leadership Conference (SCLC), led by Dr. King, Jr., James Bevel, and Hosea Williams. One of the most powerful moments of the film occurs when you see Dr. King on the archived footage for the first time, his profile coming into view after the gentleman standing next to him is preemptively pushed backwards by a law enforcement officer. The response by King's associate after being shoved? Steadfast resolution.

On February 26, 1965, Jimmie Lee Jackson was fatally wounded by a state trooper while on a march in neighboring Marion County to protest the lack of civil rights for African Americans there. The group had assembled at a local church and was marching when they were met by law enforcement officials. Mr. Jackson, unarmed, ran after the beatings began at the hands of law enforcement, but was gunned down while hiding in a local café. This moment was the catalyst for what would become the civil rights march from Selma to the state capitol in Montgomery, Alabama.

The march began on Sunday, March 7th, 1965. As Father Oulette, local parish leader states in the film, "It was an overcast, gray day. Everything seemed dead; there was no sound anywhere." When the marchers, led by John Lewis of the SNCC and Hosea Williams of the SCLC, walked over the *Edmund Pettus Bridge*, they were met by Alabama State Troopers equipped with helmets, batons, gas masks, guns, cars, and horses. Those troopers attacked the marchers with everything they had and forced the marchers' retreat back over the bridge. John Lewis, now Congressman John Lewis from Atlanta, suffered multiple lacerations on his head, among other injuries. Following this frame, Father Oulette offers a profound analogy of the civil rights marchers to that of Jesus Christ and the stages of the cross. "They were the body of Christ…they were Christ in today's Church." He continues, "They had walked the Stations of the Cross…and they had been crucified."

"Bloody Sunday" had occurred, and the Nation, through television, finally took notice. Dr. King, Jr., upon hearing of the atrocities committed by the Alabama state police, issued a national organizing call for those sympathetic to the cause of civil rights to descend upon Selma immediately.

Review

Sister Ann Christopher of Loretto in St. Louis was one of the first nuns to ask the priests of her parish if she could answer Dr. King's call and fly to Selma. Sister Ernest Marie added that she received word from her monsignor that "It was time for the Church to become visible." Both women would be part of the first group of six nuns to travel to Selma to participate in the marches. Other sisters in the original group included Sister Mary Antona, Sister Thomas Maguerite, and Sister Christine Mary of Loretto. The first group arrived in Selma that Wednesday, March 10th.

Sister Mary Antona possessed a special quality that made her different from all but one of the other nuns accompanying her—she was an African American herself. One of the most meaningful moments in the film occurs when she steps into the church in Selma and Andrew Young (SCLC), standing at the podium, looks up and is reported to say "Ladies and gentleman, one of the great moral forces…has just stepped in the door." That force was Sister Antona. Bearing witness, she gave great power to the movement with her personal experiences. Just a few days before, she actually went to vote in St. Louis before traveling to Selma, and referenced that in a strikingly remarkable observation.

Not all Catholic dioceses across the country appreciated stirring the social pot of justice. For example, an interesting pivot in the movie occurs when the Sisters of St. Joseph of Rochester (SSJR) begin to detail their experiences in Selma. The SSJR had been in Selma for a very long time already, having been missioned to provide social services to the minority populations of Selma. Sister Mary Paul, the Convent Superior at the time, provides that her convent was under strict orders from the Archbishop not to participate in any protests or marches. If anyone from the convent was discovered to be participating, they would be sent back to Rochester, New York, immediately. Of course, the ethical dilemma these nuns were forced into upon hearing this non-participation order was extraordinary.

On March 21, after federal court intervention allowed for the march from Selma to Montgomery, approximately eight thousand protesters arrived to start the march in Selma. While that number would dwindle as the march wore on to Montgomery, one of the Catholic nuns would make it the entire march; her name was Sister Mary Ann Sommer. The route that the march took brought the protesters through Lowndes County, or what one described in the film as a "Ku Klux Klan hotbed." National Guardsmen who were escorting the marchers were told to keep their eyes peeled for snipers in the bush surrounding the route. This is yet another example of the risk-taking these people, white and black alike had to take to assert their civil rights.

On March 25th, 1965, on the steps of the Alabama State Capitol, in front of an estimated twenty-five thousand people, Dr. King, Jr. delivered his now legendary "How Long, not Long" speech. Five months later then President Lyndon B. Johnson would sign into law the Voting Rights Act, formerly prohibiting any qualifications testing requirement for voter registration.

Reflections: The Healing That Is Justice

"Our place was to be with them, not to be instead of them, not to be leading them, not to be recognized for what we did," Father Oulette sums up. "We were silent witnesses… and we were privileged to be here."

Unfortunately for some of the Sisters, they were not simply silent witnesses. Upon returning to their parishes, they were subject to disdain and outright contempt for their perceived participation in something they did not understand. Members of the clergy did not support them. Members of their own convents turned their backs. Members of the public ridiculed their actions as being something the Catholic Church would not approve of from its official ranks.

However, what these *Sisters of Selma* did was the most "catholic" thing, the most enduringly "universal thing" (i.e. the original meaning of the term, "catholic) any human being has the ability to accomplish. Specifically as human beings, when one bears witness to another's pain and suffering at the hands of injustice, you have delivered to that person the best form of treatment available—to know they are not alone at their darkest moment. And through that witnessing, you are able to forward the notice of that injustice along and tell the story to others, magnifying the lens placed upon the party engaging in injustice. What is so immensely powerful about this film is the way in which the original sisters and all those who followed them eventually in all of the protests gave flesh to their strong and powerful commitments to serve those in need. Hence, as we look at so many factors in today's current events, the power of *Sisters of Selma* is not just in its accurate portrayal of a dynamic set of historical incidents. Rather its power is also found in its ability to catapult one's individual imagination and personal resolve to do everything possible to break down the chains of oppression that our neighbors may be experiencing. This may not be in the public forums the film presents. It may be in the more quiet but equally powerful interactions and relationships that happen in one's neighborhood or workplace. *Sisters of Selma* is not a film at all. Indeed it is a mirror.

Injustice is predicated on many different factors. Whether the injustice is racial, religious, economic, or sexist, the wounds left are agnostic to the cause. Those wounds are carried not by an individual, but by a society; for all that constitutes a society is but a group of individuals. Hence, the potency of this film is directly important for all those who are engaged in healthcare. Too often, we think of healthcare as the ability to heal wounds or treat diseases of individuals on the physical or psychological level. This film transforms and stretches our imaginations to re-think what we mean by woundedness and what we mean by healing. The wounds of human life can often be spiritual as well. They also are inflicted not just on individual persons but on families and on communities—indeed in cultures, nations and across the globe. This film calls us truly to be transformed—to imagine a deeper sense of healing and a deeper sense of what it means to be healthcare providers. As we take the time to look again and again into the mirror that is *Sisters of Selma*, we will undoubtedly be called to re-think who we are and what we do. We will be called to re-orient completely anew the way our hands are stretched out toward others. And when that happens, *Sisters of Selma* gives new meaning to the term, "living legacy."

Errata

The following are corrections to articles published in Volume 2, Number 1 from Winter 2012.

First, on page 11 of Volume 2, No 1, in that edition's "From the Editor's Desk," the date for the cited special address of Giovanni Battista Montini before the United Nations was incorrectly listed as October 25, 1965. The correct date is October 4, 1965.

Second, Figure 4 was inadvertently omitted from the article beginning on page 81, "Global Snapshots of Treatment Abandonment in Children and Adolescents with Cancer: Social Factors, Implications, and Priorities," by Catherine Lam, Nuria Russell, and Raul Ribeiro. The omitted figure follows.

Figure 4. Selected Proposed Strategies for Abandonment Reduction Across Disease Phases

	Issues	Strategies
Initial Diagnosis	Culture	
	Perception of illness and its severity	Disseminate early diagnosis public education
	Delays and inconsistencies in diagnosis	Support primary provider training for consistent, appropriate early diagnoses
	Health beliefs; perception of diagnostic procedures	Provide adequate pain management
	Social acceptability of abandonment	Promote thoughtful, patient-centered communication
	Influence of religion / personal faith	Conduct health teaching (e.g. need for treatment and risks of abandonment)
		Involve influential leaders in discussions as appropriate
During Treatment	Culture	
	Perception of illness and its severity	Provide patient-specific teaching and updates
	Delays and inconsistencies in treatment	Ensure family and team aware of treatment plan and attempt to plan ahead (e.g. for chemotherapy orders)
	Health beliefs	Promote ongoing thoughtful, patient-centered communication
	Social acceptability of abandonment	Establish realistic, adapted treatment plan for patient
	Treatment toxicity and side effects	Promote sharing from patient "champions" and advocates
		Provide anticipatory guidance for treatment toxicity and side effects
		Promote appropriate integrated biomedical and psychosocial coping strategies
		Provide respite care for families
After Initial Abandonment	Culture	
	Perception / passing of judgment	Attempt to maintain communication, understand reasoning and invite family's return or facilitate referral (directly and through others)
	Disappointment and frustration among providers	Provide guidance if appropriate of anticipated course and potential health concerns after abandonment
		Re-visit appropriateness of palliation
		Facilitate counseling and bereavement aftercare for families & providers
Throughout Treatment	Quality of Care	
	Standards of health services	Disseminate evidence-based practices; advocate for governmental and non-governmental regional & global partnerships that include strategic planning & health training
	Costs	
	Direct treatment costs (diagnostics, treatment and supportive care)	Advocate for accessible health insurance coverage; cost-effective practices; equitable drug policies; local evidence & expertise for tests and treatment
	Direct living costs (transportation/lodging/meals)	Provide local lodging; discounted transportation arrangements
		Establish satellite clinics in areas farther from treating center
		Establish sustainable local social capital (fundraising/donation resources, etc.)
	Indirect/opportunity costs	Involve social work and/or local social capital early and help with anticipatory planning (health insurance, childcare, alternative income)