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An assessment of environmental health measures in the Deepwater Horizon Research Consortia

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Abstract

Research consortia play a key role in our understanding of how environmental exposures influence health and wellbeing, especially in the case of catastrophic events such as the Deepwater Horizon oil spill. A common challenge that prevents the optimal use of these data is the difficulty of harmonizing data regarding the environmental exposures and health effects across the studies within and among consortia. A review of the measures used by members of the Deepwater Horizon Research Consortia highlights the challenges associated with balancing timely implementation of a study to support disaster relief with optimizing the long-term value of the data. The inclusion of common, standard measures at the study design phase and *a priori* discussions regarding harmonization of study-specific measures among consortia members are key to overcoming this challenge. As more resources become available to support the use of standard measures, researchers now have the tools needed to rapidly coordinate their studies without compromising research focus or timely completion of the original study goals.

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Epidemiology, Exposure, Human health effects, Standard measures.

Introduction

Systems toxicology requires a comprehensive understanding of the myriad factors that collectively affect human health and the environment. There has been an increase in research consortia in which investigators coordinate study design to explore different facets of a common concept, scenario, or potential chemical exposure, such as the Deepwater Horizon (DWH) oil spill. The National Institute of Environmental Health Sciences (NIEHS) announced investments in environmental epidemiology cohort studies in the early stages after the disaster as a unifying exposure event. This enabled downstream meta-analysis to uncover new risk loci, potential causative genes [1–9], biologic subtypes [10], and etiopathogenesis [11,12]. Meta-analysis, although powerful, results in some loss of information in order to combine data that were collected using different methodologies. If investigators use the same measurement protocols to collect data, then data can be compared directly and cross-study analysis is simplified. Study-specific measures are needed to address specific research questions; common measures are needed to facilitate cross-study analysis that will increase the effect of individual studies [13,14].

After the 2010 DWH oil spill, NIEHS launched the Gulf Long-term Follow-up Study (GuLF STUDY). Participants were adult workers who were engaged in oil spill response and cleanup work [15]. In addition, NIEHS funded four research consortia, the Deepwater Horizon Research Consortia, as academic-community partnerships to 'identify potential health effects from the DWH oil spill, examine factors that contribute to individual and community resilience/vulnerability, develop evidence promoting the health and wellbeing among Gulf coast residents, and develop capacity for improved preparedness and response activities' [16].

Measuring the effect of environmental exposures presents a unique set of challenges. There are many types of environmental exposures to consider, such as drinking water, air pollution, and exposure to various heavy metals, and the time frame for the exposure (short term, long term) is also critical. Some measurements may be direct indicators, such as scoring the severity of a chemical burn; others may be indirect indicators, such as a biomarker that is indicative of an exposure, or a microbiome profile. In addition, measurement

capabilities and methodologies continue to evolve, most notably sensors for environmental monitoring and sensors worn by individuals [17,18]. In this review, we present an analysis of environmental health measures among the Deepwater Horizon Research Consortia and commentary on the value of study-specific measures and shared, collaborative measures in coordinated environmental health studies.

Assessment of study-specific and common measures used in the NIEHS Deepwater Horizon Research Consortia

The Deepwater Horizon Research Consortia consisted of four studies investigating the long-term effect from the oil spill on the health of Gulf residents [16]. The Consortia include cohorts from a total of 4514 subjects from multiple sites in the affected areas:

- The Transdisciplinary Research Consortia for Gulf Resilience on Women's Health (GROWH)
- The Women and [Their] Children's Gulf Health Consortia (WaTCH)
- The Gulf Coast Health Alliance: Health Risks related to the Macondo Spill (GC-HARMS)
- The Health Impact of Deepwater Horizon Spill in Eastern Gulf Coast Communities (adults in Florida and Alabama counties) (GC-FA)

Assessment methods

In this study, we analyzed publications from the Deepwater Horizon Research Consortia to assess the similarities and differences of the measures used among the studies. For this review article, measure is a concept or construct, and measurement protocol is the precise methodology used to collect the data. The concept is that data collected by different studies, using the same measurement protocol, will be directly comparable.

The process of assessment involved the following procedures: (1) identify the primary publications for each of the four consortia studies; (2) extract the primary outcome and exposure measurements from the 'Methods' and 'Results' sections of the reviewed publications; (3) organize measurement protocols (e.g., Edinburgh Postnatal Depression Scale [EPDS]) into conceptual groups (e.g., depression); and (4) for different measurement protocols, compare the individual questions and the overall findings for a common concept. For example, we compared individual questions 'I felt depressed' to 'Feeling down, depressed, or hopeless' and 'Unhappy' and identified them as identical or comparable concepts [19].

Assessment results

The Deepwater Horizon Research Consortia studied multiple outcomes including depression, mental distress, domestic conflict, behavioral health, and pregnancy complications to look for possible associations with environmental exposures caused by the oil spills [20–25]. They also considered disease risks from chemicals due to seafood consumption in oil spill–affected areas [26–29] as well as community vulnerability and resilience [16,30,31]. The Gulf Coast Health Alliance was formed to study the health risks from the oil spill with multidisciplinary, multi-institutional academic partners and representatives of three communities [23,26]. We reviewed measures used to assess health outcomes, chemical stressors and nonchemical (psychosocial) stressors, and community resilience.

Health outcomes

The Deepwater Horizon Research Consortia studied psychological responses and mental health, miscarriage, and infertility. Mental health was assessed with different measures in the four studies, as listed in Table 1.

Of the diverse mental health outcomes measured by the four studies, 'depression' is the only one measured in all four studies. After reviewing the measurement protocols used for 'depression,' we found that each study used a different measurement protocol. The measurement protocols for 'depression' assessment were the following:

- EPDS [32,33], 10 questions
- Center for Epidemiologic Studies Depression Scale [34,35], 20 questions
- Patient Health Questionnaire [36], 8 questions
- Profile of Mood States [37,38], 40 questions

Each protocol had unique questions that were needed for a specific population or application (e.g., EPDS for pregnant and postpartum women). These protocols address similar concepts and correlate well with each other at the protocol level, although the individual questions are different. At the individual question level, the four protocols have a total of 78 questions. Analysis

Table 1 Mental health measures collected are diverse among the DWH oil spill studies.

Measure	GROWH	WaTCH	GC-HARMS	GC-FA
Depression	+	+	+	+
Posttraumatic stress disorder	+		+	+
Anxiety	+		+	+
Resiliency/coping			+	+
General distress		+		
Domestic conflict	+	+		
Mood states				+

DWH, Deepwater Horizon; GROWH, Gulf Resilience on Women's Health; WaTCH, Women and [Their] Children's Gulf Health Consortia; GC-HARMS, Gulf Coast Health Alliance: Health Risks related to the Macondo Spill.

of these 78 questions across the four studies finds that 0 questions are common for all 4 studies, 7 (12.3%) for 3 studies, 7 (12.3%) for 2 studies, and 43 (75.4%) are unique to their own protocol. Although the assessment of 'depression' may correlate well among the protocols, the specific questions asked were quite different.

Environmental exposures

Environmental exposures can be characterized into chemical stressors and nonchemical (psychosocial) stressors. A massive oil spill can result in human exposure via contact with skin, inhalation, or ingestion of contaminated water or seafood. Examples of chemical stressors are polycyclic aromatic hydrocarbons (PAHs) [27,29], cadmium [39], and mercury [28]. Examples of nonchemical stressors are physical and economic conditions [20,23,24,40]. In the case of the DWH oil spill, the consortia measured both types of stressors.

The consortia collected seafood and analyzed them for the presence of oil compounds. Wickliffe et al [29] evaluated the potential for exposure to PAHs via consumption of contaminated finfish and shellfish; Stuchal et al [27] performed a similar study using fish, shrimp, blue crab, and oyster. Zilversmit et al [28] analyzed other chemicals, mercury, and n-3 polyunsaturated fatty acids from human blood; a slightly different approach than was used in the two studies that studied PAHs from seafood. The consortium chemical work group coordinated and used the same assay methodologies for this key step in the exposure assessment.

The consortia assessed the measures of physical and economic exposures resulting from the oil spill slightly differently. Table 2 lists the common and study-specific questions. Of 24 total questions, 15 are shared and 9 are unique (denoted by *). These studies coordinated their efforts through a work group and promoted a better understanding of the long-term and cumulative health effects from environmental exposures from oil spills with this mixture of common and study-specific questions [20,22–24].

Community resilience

'Community resilience' became part of the lexicon of disaster management after Hurricane Katrina (2005) caused the affected area severe damage from a combination of community stressors, aging infrastructure, and an extremely hazardous event [41]. The 2010 DWH oil spill hit the same area, and the Deepwater Horizon Research Consortia had a component dedicated to community resilience. The community resilience working group developed a cross-consortia resource which included 68 measures or constructs for assessing community resilience. As a result, the consortia have developed the Resilience Activation Framework to promote adaptation and rapid recovery in postdisaster settings [36]. This framework articulated the resilience attributes organized in four types of 'capital' — human, economic, social, and political — at community and individual levels. In addition, the WaTCH study developed a structural equation model to assess the contributions of structural social capital, cognitive social capital, social support, and physical and economic exposures on depression [38]. A recent report analyzed community resilience measurement efforts and identified gaps and challenges associated with them. The scientific community agreed on the key components that needed to be measured to effectively measure resilience [41].

Table 2 Measures of nonchemical stressors: physical and economic exposure to the DWH oil spill — common and study-specific questions.

GROWH [20] (Table 2)
Worked on cleanup
*Used area along the coast
Property lost/damaged
Oil spill directly affected hunting, fishing, gathering
*Someone close to you injured or killed
Direct contact with oil
Financial effect
WaTCH [40] (Table 2)
*Oil spill caused damage to areas fished commercially
*Could smell oil
Came into physical contact with oil in other ways (e.g., during home, recreation, hunting, fishing, or other activities)
Oil spill directly affected recreational hunting/fishing/other activities of household
Worked on any oil spill cleanup activities
Any property lost or damaged because of oil spill or cleanup
*Oil spill had somewhat or very negative influence on household financial situation
Lost household income as a result of employment disruption/closing of business due to oil spill
*Hit harder by oil spill than others in community
GC-HARMS [23] (Table 1)
Unemployed
Lost income
*Changed living situation
Directly exposed to spill
GC-FA [24] (Table 1, 'Methods')
*Working in the fishing/seafood and tourism/service industries
Have you lost any income since the oil spill?
*What has been the biggest effect of the oil spill?
Spill cleanup participant

*study-specific questions

Study-specific measures

The consortia studies used a mixture of study-specific and common measures, although most were study specific. In the health outcome research, four different protocols (EPDS, Center for Epidemiologic Studies Depression Scale (CES-D), Personal Health Questionnaire Depression Scale (PHQ-8), The Profile of Mood

States (POMS)) were used to measure 'depression'. We also found many study-specific measures in Prestige and Hebei Spirit oil spill studies, as summarized in a review article by Laffon et al [42]. Investigators justify the use of study-specific measures for a variety of reasons including (1) study-specific measurement protocols may be needed to address specific populations and/or areas; (2) questions from common measures that are irrelevant cause participant burden with a longer interview; (3) for community-based participatory research, local knowledge, rather than standard measures, may be more valuable; (4) extra time to identify and become familiarized with standard measurement protocols beyond the ones investigators have always used leads to an extended timeline that poses budget and timeline pressure for time-sensitive studies needing to get to the field as quickly as possible; and (5) investigators gain scientific incentives when they move their own work forward with publication.

There are some additional reasons why it is difficult to define common measures for exposure studies. First, many exposures are estimated from location and activity information, which rely on participants' recall rather than direct measurement. This increases the likelihood that metrics developed in different laboratories or research groups will vary more widely than for protocols where a direct measurement is made. Second, the strong need for longitudinal data covering decades means that investigators may be hesitant to change metrics for existing cohorts to accommodate the shared research questions among the studies within consortia. Consortia have typically compensated for the lack of common measures by assembling aggregate models consisting of the related measures collected across consortium members [13,43,44].

Naturally, a study would use legacy measures for consistency, either measures used in a cohort previously or measures used in previous events. In the present case study, measures for oil spills were adopted from previous oil spill studies, such as the Gulf Workers' Study and studies of the Exxon Valdez oil spill [45]. Measures for natural disaster experience were adopted from studies for Hurricane Andrew and Hurricane Katrina but addressed Hurricane Rita, Hurricane Ike, and Hurricane Gustav; Mississippi flooding; and Hurricane Isaac [20,46]. The four studies in the Deepwater Horizon Research Consortia used legacy measures for their own cohorts to address cohort-specific exposures and issues, and many of the measures are study-specific.

The Deepwater Horizon Research Consortia required a community resilience component of academic-community partnerships for community-based participatory research, which often necessitates addressing local community concerns to maximize the effect on these communities affected by the disaster. Using the diverse study-specific measures collected from the four studies, the community resilience working group developed the Resilience Activation Framework by organizing dozens of measures at the community and individual levels into a conceptual model. These measures contribute to four domains: human capital, economic capital, social capital, and political capital. The dozens of data elements for each domain are different at the community and individual levels. For instance, the community level of 'economic capital' contains 'median household income,' 'tax revenues,' 'employment,' and 'occupational diversity,' and the individual level contains 'household income,' 'savings,' and 'access to credit or loans.' Most of these data elements were measures by protocols specific to each study [30].

Common standardized measures

While taking advantage of study-specific measures collected by each study, the consortia also carried out the effort of 'standardization' by putting in place discipline-/domain-specific working groups. The community resilience working group developed a list of psychosocial measures shared by the studies, and the exposure working group developed standardized analytical chemical methods for PAH sampling in seafood. Including some common key environmental exposure measures for consistent data across studies can increase the scientific impact of individual studies and is often not obvious and neglected during study design. The National Institutes of Health (NIH) Common Data Elements (CDE) Repository (https://cde.nlm.nih.gov/home) provides several NIH common measures and CDE resources focusing on a variety of disease topic areas. DeBord et al [47] described the concept of the exposome with three domains of the exposome (internal, specific external, and general external) summarizing the various sources of exposures and their possible correlation, as well as the challenges in measuring the exposome because of the diversity and variability over time. Patel et al [17] presented opportunities and challenges for environmental exposure assessment in population-based studies, with an analysis of traditional and emerging environmental and behavioral measurement modalities to capture indicators of exposure.

A recent report published on building and measuring community resilience [41] analyzed resilience measurement efforts and identified gaps and challenges associated with them. One of the findings in this report stated that the data among the community organizations are not compatible, making it difficult to integrate measurement activities across sectors. Thus, one of the eight recommendations stated "Communities should ensure that the data collected, integrated, or synthesized for community resilience are relatable and usable for decision making." The report recognized a need for community-specific and common standard measures to effectively evaluate community resilience. A'core' set of general community resilience measures that are

complemented by community-specific measures can fill the gap of data compatibility and help with data collection, integration, and synthesis to support decision making.

Opportunities for collaborative environmental studies

Studies need to include study-specific measures to address specific research questions and to accommodate specific populations. However, it is becoming clear that the inclusion of (common) measures that facilitate cross-study analysis can increase the effect of individual studies [13,14]. For this reason, several large collaborative research initiatives are expecting use of common (standard) measures. Programs, resources, and initiatives that are promoting the use of common environmental exposure measures include the following:

- **NIH Disaster Research Response Program** was created to create new tools, protocols, networks of researchers, training exercises, and outreach involving diverse groups of stakeholders. The goals are to help overcome the challenges of disaster research, improve the ability to collect vital information, reduce adverse health impacts and improve future preparedness (https://dr2.nlm.nih.gov/) [48].
- **PhenX** (consensus measures for **Phen**otypes and e**X**posures) is a community-driven effort that identifies and recommends measures for use in genomic, clinical, and epidemiological research. The PhenX Toolkit is a web-based catalog that presents these recommended measurement protocols and provides tools to help investigators incorporate these protocols into their studies (https://www.phenxtoolkit.org/) [49].
- **Environmental influences on Child Health Outcomes (ECHO)** supports multiple, synergistic longitudinal studies using existing study populations to investigate environmental exposures — including physical, chemical, biological, social, behavioral, natural, and built environments — on child health and development. The measurement protocols from existing studies and the ECHO-wide cohort data collection protocol include many assessments of environmental exposures (https://www.nih.gov/research-training/environmental-influences-child-health-outcomes-echo-program) [13,44].
- **Children's Health Exposure Analysis Resource (CHEAR)** and **Human Health Exposure Analysis Resource (HHEAR)** are centralized networks of exposure analysis tools, services, and expertise to support NIH-funded researchers studying human health (https://www.niehs.nih.gov/research/supported/exposure/chear/index.cfm). The CHEAR Ontology summarizes a broad range of environmental exposures measures (https://bioportal.bioontology.org/ontologies/CHEAR) [50,51].

These examples indicate that funding organizations recognize the importance of standard (common) measures to increase the impact of individual studies and to increase the overall impact of large interdisciplinary consortia and initiatives. By investing in these types of programs, resources, and initiatives, NIH is developing a framework that will encourage investigators to incorporate common measures, alongside their critically important study-specific measures, especially at the study design phase. Inclusion of common (standard) measures in addition to conceptually related legacy measures provides a 'data bridge' to quantitatively combine or effectively compare data collected using the different methodologies.

Human health and wellbeing are determined by myriad lifestyle choices and environmental exposures in the context of people's genetic predispositions from birth. Advances in our understanding of these individual factors, coupled with increased computational capacity, enable integrative models that account for the many possible causes of disease rather than studying subsets in isolation. The data requirements for this approach are too great for any individual study, however, making it critical to maximize our ability to integrate data across studies.

Conclusions

Analysis of environmental exposure and outcome measures among the Deepwater Horizon Research Consortia studies suggested that study-specific measures are necessary and valuable to address local community concern, and common measures facilitate the ability to combine data from conceptually related studies. Meta-analysis depends on the ability to combine information gleaned from data that is not directly comparable, via a data harmonization process. Data harmonization is known to be a laborious task [52]; collection of data that are directly comparable avoids the need for data harmonization. Studies focused on a natural disaster such as the DWH oil spill represent a unique challenge given the short timelines and the need to address questions that directly affect the disaster response. This makes efforts such as the NIH Disaster Research Response Program, which can prepare standard measures and data harmonization workflows for study-specific measures in advance, a critical resource moving forward. With a concerted effort among funding agencies, study investigators, and resources such as PhenX and the NIH Disaster Research Response Program, data generated from large research consortia can provide a better fundamental understanding of biological systems and their interactions with the physical environment while still answering the key questions that motivated the individual studies.

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Conflict of interest statement

Nothing declared.

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