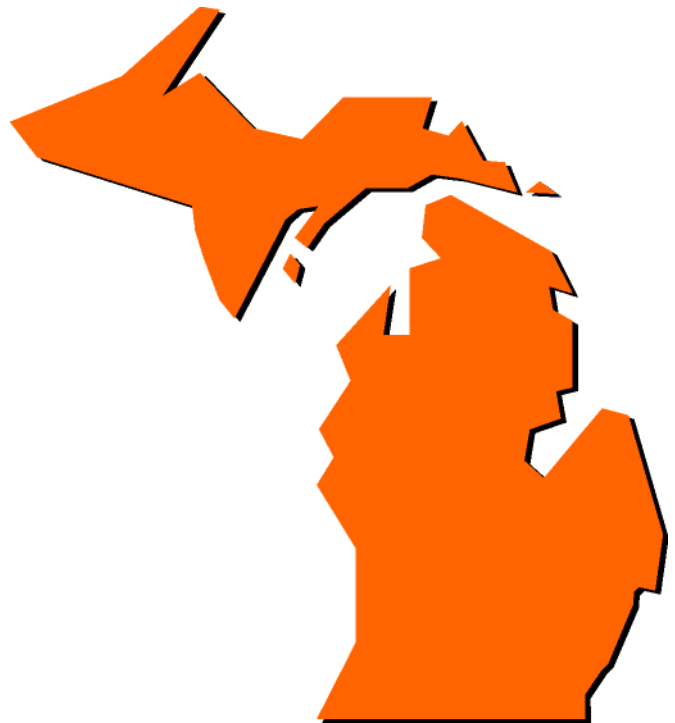


Michigan Journal of Public Health



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The mission of the Michigan Journal of Public Health is to promote public health practice, research and policy with specific focus on Michigan and the Great Lakes Region. We encourage contributions from the field of practice, original research, opinion and commentary. It is the expressed interest of this Journal to encourage dissemination from the field of public health practice.

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Letters to MJPH

Dear Michigan Journal of Public Health Readers:

National journals helped get us through school, and they continue to keep us current on national issues. But there is an important place for local public health journals as well. Often the major projects, interesting research conducted locally, and recognition for local practitioners gets overlooked at the national level. The Michigan Journal of Public Health will be the place that you can report significant projects, community campaigns, interesting Michigan-based research, and local strategies for dealing with Michigan and the Great Lakes Region public health problems. The journal will also provide a special place to recognize the accomplishments of Michigan public health practitioners. As you share a border with Canada, you might also invite an international discussion of common issues along the border. Students in public health should be encouraged to submit to the journal, giving them valuable experience in writing for publication. You have good representation on the editorial board and a wonderful, diverse state to cover. Michigan's balance of urban, rural, academic, and environmental issues will provide wonderful subject matter for the journal. Please accept my warmest congratulations on the inaugural issue of the Michigan Journal of Public Health.

Patricia D. Mail, PhD, MPH, CHES
President, American Public Health Association
Tacoma, Washington

JOHN B. WALLER, JR, DrPH: A CELEBRATION OF LIFE IN PUBLIC HEALTH
A TRIBUTE IN THE MICHIGAN JOURNAL OF PUBLIC HEALTH

Michigan Journal of Public Health Editorial Board



John B. Waller, Jr, DrPH, Vice-Chair of the American Public Health Association from 1999-2000, and a former Chair of the WSU Department of Community Medicine passed Thursday, January 5, 2005, in Detroit. David Satcher, MD, PhD, President of the Morehouse School of Medicine, 16th United States Surgeon General, and an esteemed colleague of Dr. Waller, stated "Dr. Waller will always be appreciated for his ability and commitment to put a community face on public health. Hopefully, public health will always reflect this 'community face.'"

Dr. Waller was one of the nation's first researchers to treat interpersonal violence as a public health issue. He redefined the phenomenon as an epidemic rather than a societal problem intrinsic

to poor, inner-city areas. His focus on population-based epidemiologic characterization encompassed interpersonal violence as well as maternal-child health, chronic and disabling conditions, and minority health.

Although Dr. Waller's academic credentials were exemplary, his heart was in community health. He was a founding member of the Detroit Community Health Connection and the Detroit Healthcare for the Homeless, multi-site primary care Federally Qualified Health Centers, as well as Community Health Awareness Group

(CHAG) in Detroit. Dr. Waller also served as Chair of the Detroit Empowerment Zone Corporation, and the Greater Detroit Area Health Council.

He was known as “Dr J.” After serving in the Air Force, he received a football scholarship, graduated from Temple University and began a career as a microbiologist. Dr J was a decisive man. He met the love of his life, Mikki, at a Philadelphia church choir and they were married within two months by his father, the Reverend John B. Waller, Sr. Dr. J and Mrs. Waller remained vibrant partners for forty-two years. He went on to receive his Doctorate in Public Health from the University of Michigan and then relocated to Newark, where he served as Public Health Director for five years. In 1978, he was recruited to return to Detroit as Public Health Director for the City. He subsequently played a critical role in forming the partnership that created Detroit Receiving Hospital and the University Health Center. He held the position of Senior Vice President for Urban and Community Health for the Detroit Medical Center (DMC), directed the DMC/WSU Community Health Institutes, and was a committed member of the WSU faculty for more than twenty years.

Dr. Waller was recognized through many awards, including the WSU Distinguished Service Award and the Pathfinders in Medicine Award. He continues to be honored with the dedication of the Detroit Healthcare for the Homeless “John B. Waller, Jr. Health Care for the Homeless Center” at 2395 West Grand Boulevard in Detroit.

Editorial

Welcome to the first issue of the Michigan Public Health Association's (MPHA) new peer-reviewed journal, the *Michigan Journal of Public Health* (MJPH). It is the hope of the members of the MJPH Editorial Board, all of whom are members of MPHA, that you will find this journal of great value. It is designed to provide MPHA's membership and the broader community of public health in Michigan a source of and an outlet for articles related to the practice of public health in Michigan and the Great Lakes region. We also hope this journal will serve as a neutral forum for the discussion of ideas and issues that are important to the current and future of public health practice in Michigan.

We live and work in a state with a long and strong tradition of public health practice at all levels of governance, and for excellence in public health research and workforce development. The MPHA has determined that this tradition is overdue for the development of a peer-reviewed journal that both celebrates the best of this tradition, and also encourages further growth.

Going forward MJPH will be published in an electronic format twice a year. We invite all in the field of public health in Michigan, from local public health, state public health, academia, and the myriad of other organizations that engage in public health activities, to consider submitting practice articles, commentaries and letters to the editor for publication. This journal is first and foremost a journal dedicated to the practical, day-to-day practice of public health in our state.

Both the Board of MPHA and the Editorial Board of the MJPH are seeking funds to move the MJPH to a true on-line journal format. We hope to have this process completed prior to the publication of our fourth issue, which will occur in June of 2008. Until that time, we will publish this journal in the format as you see it today.

We encourage you to share this copy of MJPH with your colleagues. This issue and all future issues will be posted on the MPHA website, and will be available to all. This access will change slightly when we move to a true on-line format. At that time the MJPH will move behind into a new members only web page behind the MPHA main page. Be assured you will still be able to share articles of interest with non-MPHA members at that time by e-mail links to specific articles to colleagues.

Lastly, please take notice of the feedback form at the end of this issue. Please consider copying this form into a new document, filling it out and e-mailing the completed form to mijph@hotmail.com. We would greatly appreciate your input!

We hope you had a wonderful holiday season, and we look forward to hearing from you

RESEARCH AND PRACTICE

Public Health Emergency Preparedness Terminology: Using an Interactive Game to Introduce Complex Words and Definitions.

Authors

Julie Gleason-Comstock, PhD, CHES, Tim Spannaus, PhD, Ellen Marks, MLS, Deborah Charbonneau, MLS, Alicia Streater, PhD

Key Words

Public health emergency preparedness, public health terminology, public health education, instructional games.

Abstract

Objectives. An educational reinforcement exercise, using a bingo game, introduced students to challenging public health emergency preparedness terminology in order to pilot test the use of a game as an efficient method of learning a new vocabulary and definitions. Knowledge of the language of emergency preparedness and a fast and fun way to stay current could contribute to better coordination among public health personnel and their community partners.

Methods. A bingo game, developed using Macromedia Flash and XML files, and delivered within the Blackboard™ Course Management System was tested with first year medical students in a library orientation, and graduate public health students in an introductory class (Groups 1 and 2 respectively). Pre- and post-tests were embedded in the game so that participants received their results at the conclusion of each to reinforce learning.

Results. Both groups showed a statistically significant improvement in their knowledge of terms.

Conclusions. The results suggested that the web-based educational reinforcement in bingo game format was an effective method for learning difficult terminology. Anecdotal data from verbal feedback after each group showed favorable reactions to the learning approach. The flexibility and customizability of the bingo activity makes replication in other academic and public health applications possible.

INTRODUCTION

Public health has been increasingly recognized in recent years because of its critical role in emergency preparedness for epidemics, bioterrorism and natural disasters. Local public health agencies are often charged with managing these complex shared community responsibilities (Asch et al., 2005; Quiram et al., 2005) and must coordinate across the spectrum of public health communities and disciplines (Markenson et al., 2005; Covich et al., 2005). Diverse social, economic and biological factors necessitate partnerships between governmental agencies and private entities. Sharing a common language is a central component of effective coordination. A review of the literature shows little research has been conducted in academic settings using web-based terminology to introduce Public Health Emergency Preparedness (PHEP) terminology.

“Public Health Emergency Preparedness: Matching Fact to Function” was designed as a minimalist educational model to efficiently disseminate public health emergency preparedness (PHEP) terminology. The model was tested in a medical school with a public health program, diverse student population and urban

international border location. The primary activity was a Web-based educational reinforcement exercise in bingo game format, developed in Macromedia Flash. The BlackBoard™ course management system enhanced the model with a pretest and posttest. The literature suggests a game format would be effective with this population (Gee, 2003; Beck & Wade, 2004) and for this content (Thiagarajan, 2003; Quinn, 2005).

The model used is based on the “knowledge proficiency” level, or ability to define and match terms and definitions (Bloom, 1956), a narrower focus than many online programs which include full curricula and exercises (Baldwin et al., 2005; Parker et al., 2005; Terndrup et al., 2005). While traditional emergency preparedness and response (EP&R) terminology and public health (PH) terminology share a common foundation, important terms/concepts are continuously being added; moreover, there are some terms with different connotations for the respective fields. Key terms were chosen from the Centers for Disease Control and Prevention’s (CDC) Emergency Preparedness & Response (EP&R) Web site, a Critical Incident Protocol glossary, and graduate public health lectures (CDC, 2005; Jones, 2004; Bhalla & Warheit, 2004). Although it was not possible for the activity to be inclusive of all appropriate terminology, a reasonable effort was made to select representative vocabulary. Examples of important terms for EP&R which may not be traditionally used in PH are “Unified Command Center” and “Incident Commander.” Important terminology in PH that may not be as familiar in EP&R is disease “incidence” and “prevalence.” Examples of terms familiar to both traditional public health and emergency preparedness, but with potentially different connotations, include “domestic violence,” “recovery” and “exercise.”

METHODS

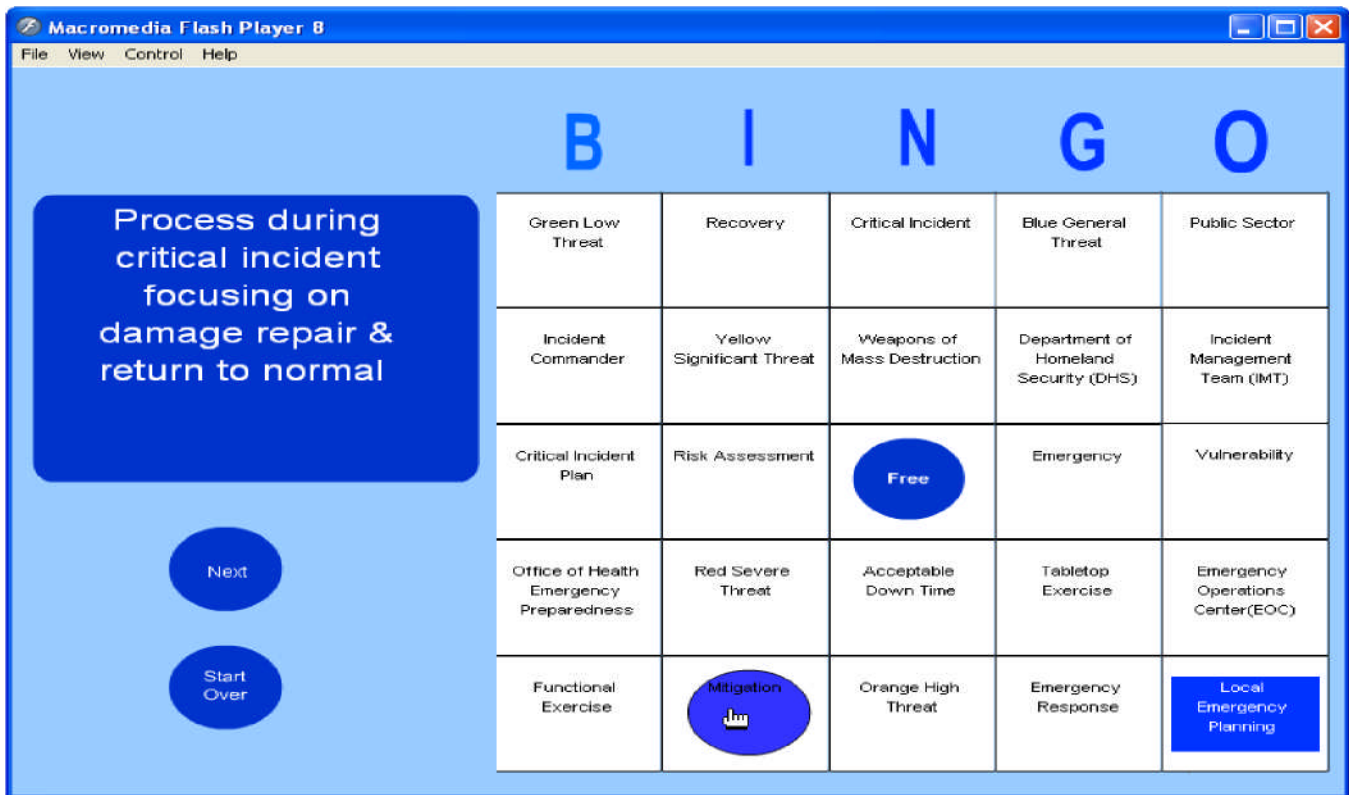
The learning technique was tested in two sample groups. All participants were members of a larger group who were attending either an orientation meeting or an introductory class. In the first group, 208 first year medical students attending a scheduled medical library orientation were offered the opportunity to participate. Of these 195 (93.7%) participated in the learning exercise. In the second group, 21 of 31 Masters of Public Health first year graduate students attending the introduction to public health class were given the opportunity to participate, yielding a response rate of 68%. The two activities were done about a month apart.

Procedures

The learning activity was conducted in medical library computer classrooms so each participant could have their own computer. The Blackboard course management software was used to present the pretest and posttest and provided automatic scoring and immediate feedback. The activity was a sanctioned addition to end of the orientation or class. Students received a recruitment script which explained the voluntary nature of their participation. If they chose to participate, they subsequently received an information sheet explaining that only aggregate data would be reported and published. Participants were enrolled in the activity using BlackBoard and an instruction sheet led them to the locations of the pretest, the bingo game and the posttest. Although participants completed the three components at their own pace on individual computers, the total time allotted for the game and activity was 30 minutes.

The bingo format offered rapid reinforcement of correct or incorrect answers. Terms and definitions in XML file format consisted of 42 paired terms and definitions. Each participant received randomly selected definitions which they had to match to terms. For example, the definition “Location senior public officials assemble to resolve critical incidents” would match with the term “Emergency Operations Center.” With only 24 squares on the “bingo card”, not all terms were on the board at all times. If the student determined that no term matched an available definition, s/he proceeded to the next definition. If the term was on the board and was accurately selected, a “piece” appeared on the appropriate bingo square. If the student completed an entire row horizontally, vertically or diagonally, s/he was alerted to the successful completion of the exercise. Figure 1 is illustrative of the matching definitions to terms format.

Figure 1: The PHEP Bingo Board: An Educational Reinforcement Exercise



The pretest and posttest each had six questions; some questions were worth ten points and others were worth five. The questions were presented in three formats: multiple choice, sequential ranking or fill-in-the blanks. Examples included:

- An exercise with limited field operations, simulation testing, preparedness and resources deployment is:
 - a) Full scale
 - b) Functional
 - c) Tabletop
- Place emergency threat levels in their proper sequence from low to severe:

Orange, red, yellow, green, blue
- Identify the federal agency responsible for safety of the food supply and biologic efficacy.

(Type in answer)

Both groups received a five minute introduction to the topic of PHEP. However, there were some differences between the groups in the sequence of activities. Participants in the first group were immediately asked to complete the pretest, the bingo activity, and the posttest. In contrast, the participants in the second group first heard an hour lecture by an urban health coordinator on PHEP implementation and its relevance to Public Health core competencies prior to completing the pretest. This lecture was not intended as an enhancement to the learning activity protocol; it was the regularly scheduled topic for the class.

All participants received a summary score and feedback on their responses immediately upon completion of each assessment. Therefore, participants knew their pretest scores and the correct answers to the questions before engaging in the bingo game and completing the posttest. Participants from both groups received a Public Health Emergency Preparedness Common Terminology Study Guide for the terms used in the bingo activity after completing the learning exercise.

Investigators were available for technical assistance for Blackboard course enrollment and the game. This procedure enabled observation of the patterns of difficulties experienced by some of the participants to aid in future improvement of the game. Although a formal satisfaction survey was not used, verbal feedback was encouraged at the end of each group.

RESULTS

Identifiers were stripped from the pretest and posttest scores and downloaded into a SPSS database for analysis. The maximum number of points a participant could receive was 50 for the pretest and 50 for the posttest. Actual pretest scores ranged from 4-45 in Group One and from 2-45 in Group Two. Posttest scores ranged from 5-50 in Group One and 20-50 in Group Two.

Not all participants had both pretest and posttest scores. This may be due to problems with Blackboard registering the responses or participants choosing to skip either the pretest or the posttest assessments. In Group One there were 179 (92%) who completed both the pretest and the posttest assessment. In Group Two, there were only 16 (76%) who completed both assessments. Paired t-tests were conducted separately for each group based on the participants who completed both assessments. Table One displays the results.

Table One: T-test Comparison of Pretest and Posttest Mean Scores

	Pretest Scores	Posttest Scores	t-test	p
Group One n = 179	21.87 (8.4)	36.51 (9.9)	-15.834	<.00
Group Two n = 16	23.63 (10.4)	36.56 (8.3)	-4.189	.001

As can be seen in the table, both groups showed a statistically significant improvement in their knowledge of terms. The average increase for Group One was 14.6 points and for Group Two it was 12.9 points. Pretest means for Group 2 were slightly higher than Group 1; however, posttest scores were almost identical.

DISCUSSION

The significant increase in scores for both groups suggests that the pairing of the bingo game and technology was an effective learning mechanism for PHEP terminology. The slightly higher increase in scores found in Group One could be due to a variety of factors. The participants in the first group were first year medical students who may have been less likely to have prior knowledge of public health terminology than the MPH students. Also the addition of the one hour lecture could have impacted Group Two's pre-activity knowledge of the terminology, causing their pretest scores to be higher than Group One's.

The intervening lecture in Group Two was not intended as an enhancement to the intervention but rather was an artifact of the classroom environment. Because differences in the posttest scores between the two groups appear negligible, there is no evidence to suggest that the inclusion of the hour lecture had significant effect on the learning exercise.

The two samples were chosen to test the learning activity because of the introductory content of the respective group sessions and their relevance to public health. No effort was made to control for group size.

Limitations

No data were collected about the participants themselves nor of their interests or background in public health emergency preparedness. Therefore, it is impossible to determine if there was a response bias due to self-selection or to prior knowledge of the terminology. Also it is unclear if the results are generalizable to the general population. However, the replication of the findings in Group Two lends some support to the generalizability of the effectiveness of the teaching method to other populations.

CONCLUSIONS

Increases in knowledge in both participant groups suggest that the approach and technologies used warrant further investigation. Anecdotal data from verbal feedback after each group indicated that the general response was favorable. Overall the students enjoyed the activity although some of them expressed the desire for "more time" due to their lack of familiarity with the terms.

PHEP vocabulary is abundant in acronyms such as ICS (Incident Command System), EOC (Emergency Operations Center), and POD (Point of Dispensing). Acronyms for federal, state and local agencies such as the Department of Homeland Security (DHS) or Local Emergency Planning Committees (LEPC) are also used frequently. Participants recommended that special attention be paid to acronyms in the future, perhaps as a discrete game.

Future plans include availability of the web-based educational reinforcement activity for dissemination through public health courses. The application of interactive game-based learning as a component of an online, distance education course and/or professional continuing education will also be explored. Because of the dynamic nature of the field, the vocabulary continues to be expanded, a process made easier by the storage of terms and definitions in XML format. MPH students participated in terminology updates through their review of US Department of Health and Human Services National Institutes of Health (NIH), and Health Resources and Services Administration (HRSA) web sites and publications in class sessions after the bingo game activity. Department of Homeland Security and Department of Justice web sites will also be reviewed. PubMed Medline will be used to conduct searches of biomedical literature and other timely sources for ongoing activity enhancement.

As an adult learning methodology, the use of games as a training tool can build enthusiasm and increase positive interaction among individuals with diverse learning and communication styles (Barnett et al., 2005). From a practical perspective, it appears the bingo activity can be conducted in small or large groups, as long as individual computers are available. Because of strategic location and cultural diversity of the university, its neighboring communities and international border, multi-lingual approaches will be explored, as will "talking dictionary" techniques to support the region's common languages and the sight-impaired. Additional study



through a pretest-posttest model or focus groups could facilitate better understanding of the perceptions of students, public health professionals and community members about the use of interactive gaming technologies as a learning modality generally and for emergency preparedness learning specifically.

About the Authors:

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Contributors

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Human Participants Protection

The Institutional Review Board of Wayne State University reviewed and approved the study.

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Clinical Case Mix and other Challenges to Detroit's Medicaid-Dependent Nursing Homes¹

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Key words

nursing homes, Medicaid-dependent, long-term care, urban health care, nursing home administration, underserved minority aging, minority health care disparity

Abstract

Nursing homes that care for the poor in Detroit are frequently dependent upon Medicaid as their principal source of revenue. These facilities face numerous challenges because they face limited resources for maintenance of facilities, staff and administrative supports, and other normal costs. They lack the kinds of support that are provided in-kind, or by more generous sources of revenue and are often characterized as institutions of poor quality; yet nearly 70% of the nation's Medicaid-recipient elderly nursing home patients are in for-profit facilities that are sustained largely on Medicaid funding. These facilities are often sources of care for underserved minority populations, the adult mentally-ill, and others for whom alternative venues of care are no longer available. The case mix of aged, mentally ill, and numerous other chronic adult conditions is unlike any other health care environment in Michigan, yet the facilities that offer such care are poorly understood and insufficiently supported. The situation has established a health care disparity for the aged, urban poor.

INTRODUCTION

This project was undertaken in 2004 in order to understand the circumstances faced by Medicaid-dependent nursing homes in an environment that has witnessed several facility closures during the last five years and a shrinking of the aging population within the jurisdiction of the Detroit Area Agency on Aging. At the onset of the project the combination of a shrinking population of age-eligible, potential long-term care residents, the loss of facilities, widespread poverty, and economic decline in Detroit were recognized as likely to take a serious toll on this level of service availability for low income seniors in Detroit. Also, if the need for adequate nursing home care forced residents of Detroit, or their family members who make decisions on their behalf, to leave the City to find an appropriate nursing home placement, it would be unlikely that the patient would ever return to the City; this process was viewed as one that would contribute to the loss of population. This population loss would then be compounded by the loss of employment in a long-term care system for each lost patient, a loss of revenue to the DAAA-1-A associated with population shrinkage, and a ripple effect of other economic consequences to Detroit.

The exact proportion of Medicaid beds in PSA 1-A that is actually occupied by low income, elderly patients is not clear because eligibility and demonstration of need are not age dependent, but based on an inability to attend to activities of daily living and low income. Certainly the proportion that represent "traditional" frail elderly residents averages over time at less than 80% of the whole. In some facilities the proportion of traditional, elderly, frail is as low as 55% (Douglass, et al. 2004). If the demand for Medicaid nursing home beds in Detroit were based exclusively on the traditional elderly, frail (the traditional service population), then excess capacity and closures of beds and/or facilities would have accelerated in the last several years. Slack in the traditional demand has, however, been replaced by demand for beds from other populations, most principally the adult mentally ill for whom alternative placements are no longer available within the community. This has produced a new, non-traditional, clinical case mix in Medicaid-dependent nursing homes. The following discussion will include a review of the history of the nursing home industry in Detroit, the close historical relationship between this industry and the Medicaid program, and the methods and findings of the 2004 study regarding the emergence of a non-traditional clinical case mix that poses a serious challenge to Medicaid-dependent facilities today.

BACKGROUND

Much of the following discussion should be considered in the context of an historically based, general dismissal of Medicaid-dependent nursing homes by many stakeholder communities, be those defined as academic gerontologists, social workers, nurses, advocates for the poor, health care managers and administrators, the business community, journalists, state or county civil servants, large health care systems, elected officials, or political entities. In light of the enormous technical and academic literatures dealing with geriatrics and gerontology, relatively few efforts have been launched with the goal of learning all that there is to know about Medicaid-dependent nursing homes or of the patients that they serve. Teaching, research, policy-oriented and financial aspects of the larger health care system appear to us to have been unconcerned about Medicaid-dependent long-term care facilities. It is not much of an extension to realize that this also means that the larger health care system has been largely unconcerned about a large number of highly vulnerable and poor patients who are dependent upon these facilities. The conclusion applies even within the large literature in clinical gerontology and

geriatrics where most clinically oriented research takes place in environments with far more infrastructures and resources than the average Medicaid-dependent nursing home.

The majority of nursing home patients, however, live in Medicaid beds, and the majority of these are in largely Medicaid-dependent facilities for which Medicaid is the dominant source of revenue. It would appear then, that much of the literature and professional guidance is of little relevance to those who serve most of the elderly, frail and poor that live in Medicaid-dependent facilities. Upon assessing the extensive literatures from gerontology, nursing, health economics, public health, social work and geriatric medicine, we recognized that only a small portion of all studies on nursing homes, quality of care in long-term care, specialized care of Alzheimer's Disease, other dementias, regulation and management of nursing homes, and other related issues focus directly on Medicaid-dependent facilities or with Medicaid patients. Most research studies in the field focus on Medicare-based services and the vast majority of nursing home studies, independent of the discipline or perspective of the investigators, are relevant to issues such as improved quality of care that are feasible only in not-for-profit, charitable, hospital-affiliated, and other relatively affluent sectors (Douglass, et al., 2004). Because Medicaid-dependent facilities and their patients are rarely the subject of serious academic research and assessment, we are compelled to conclude that much of what we "think" we know about nursing homes fails to address important questions that apply to the majority of the patients who are poor and live in facilities where such research and teaching does not take place. Therefore, most gerontological and clinical, geriatric clinical educational material is drawn from studying institutions and patients in resource-rich environments where most of the nursing home patients in the United States do not live.

The literature reflects another observation. Most academic-nursing home partnerships are hosted in facilities that are eligible to receive gifts and grants and are places where academic research and teaching activities are generally conducted; places where students learn the state of the art. This observation was also noted by Mor, et al. (2004) who concluded that, "Those writing on the quality of nursing home care have, for the most part, framed the discussion in terms of its uniformly poor quality and have largely ignored the prospects and implications of a two-tiered system differentiated by quality." (2004, p. 227)

This widespread predisposition to provide guidance based on private pay and Medicare-supported patients, and most usually within the not-for profit sector, however, flies in the face of significant realities. Again, as summarized by Mor et al., "The Medicaid program is the United States' largest purchaser of nursing home services...Medicaid's *per diem* payment rates are usually lower than others and may even be below the actual cost of providing care...Those homes that are highly dependent on Medicaid as a source of revenue have the greatest difficulty securing the resources needed to provide good quality care."(2004 p. 228-229)

The basic facts of nursing home availability, inspection-based statistics of quality assurance, analyses of closures and terminations, or state-imposed temporary management, and additional relevant matters have been subjects of several recently publications. The information for most of these analyses is based on data required by Federal OBRA regulations (Harrington, et al, 2001; Harrington, O'Meara, Kitchener, Simon and Schnelle, 2002; O'Neill, Harrington, Kitchener, and Saliba, 2003; Harrington, Mullan, and Carillo, 2004). From these analyses urban, Medicaid-only or Medicaid-dependent facilities are more likely than others to serve African American and other minority populations (Douglass, et al., 1987; Gaugler, et al., 2004; Grabowski, 2004; Mor, et al., 2004). These facilities are reported to have higher than expected proportions of men than women (Davis and LaPane, 2004; Mor, et al. 2004), and substantial resident populations who are not aged, but younger populations who are mentally ill, disabled due to trauma or chronic

disease, or suffering from late stage HIV-AIDS (Harrington and Swan, 2003; Davis and LaPane, 2004). Poverty, racial separation such as in Detroit (in the context of S.E. Michigan), and issues of populations that are growing old, frail, and alone, are ubiquitous characteristics of residents in urban, Medicaid-dependent facilities (Pourat, Anderson, and Wallace, 2001; Davis and LaPane, 2004; Gaugler, Leach, Clay and Newcomer, 2004).

Nursing home facilities that depend on Medicaid and serve the poor are more likely than suburban facilities to be owned and/or managed by for-profit corporations, to be owned and operated as a component of a corporate chain franchise structure, and to have higher numbers and severity of deficiencies as determined by State surveyors and reported to the Center for Medicare and Medicaid Services (CMS) the Federal agency that oversees the Medicaid program. (O'Neill, et al., 2003; Wheeler and Benincasa, 2003; Mor, et al., 2004; Kinchelo, 2004; Harrington, et al. 2004, 2003; Grabowski, 2004a, 2004b; Ranz et al. 2004; Davis and LaPane, 2004;). Normally standards of care through state licensing regulations set the standard of care that is expected in Medicaid participating nursing homes. This level of quality is not to be considered a "gold standard" of care as much as a minimum expectation safety standard for the residents. More highly resourced facilities, however, especially those who also participate in Medicare with Skilled Care certification, do adhere to "gold standards" of care that are above and beyond the expectations of state licensing, alone. The expectation to apply such gold standards of care in Medicaid-dependent facilities is seldom reasonable, however, because the resources, intrinsic institutional supports, multi-institutional partnerships, or cross-subsidy financing that sustain such standards are not often available in Medicaid-only or highly Medicaid-dependent facilities. In such facilities and the communities that support them, poverty, combined with complex challenges common to urban settings and minority population status are also associated with slow nursing home placements (Stevens et al., 2004), predictably lower quality nursing care (Schulz, et al., 2002), and more likely than suburban or majority residents to face facility closures, terminations, or sudden transfers to other facilities.

THE HISTORY AND DEVELOPMENT OF MEDICAID-DEPENDENT NURSING HOMES

A brief review of nursing home evolution in Michigan and Detroit will help set the stage for the following discussion. The nursing home industry, as it has evolved over the last 40 years, has been nearly synonymous with the evolution of Medicaid in the United States. Prior to the implementation of Medicaid there were few true nursing homes. While some pioneering efforts in Detroit and the metropolitan area had been serving the needs of aged and isolated people for many years, such homes were few and tended to serve somewhat specific populations such as retired teachers; unmarried, aged women; indigent and aged veterans and other groups. Most frail elderly were cared-for in family homes. It was the overcrowding of State Mental Hospitals that moved State authorities in Michigan and throughout the United States to transfer the frail mentally ill from state institutions into the community. By moving these patients into the community, not because they were old and frail but because they were poor, the states could "split the cost" of continued care the mentally ill elderly with the Federal Government. With the new Medicaid Program the states set rules for eligibility and menus of service but the Federal Government put up half the money. This would relieve overcrowding and the burden on the state treasuries.

Nursing homes as we now recognize them, were often established expressly for the purpose of taking care of the aged, mentally-ill who were deinstitutionalized into the community.

Eligibility for basic 24 hour nursing care under Medicaid was based on these populations' indigence, a consequence of many years of institutionalization. Medicare was largely irrelevant because it was conceived in an acute care model and was focused on hospital care. The movement of tens of thousands of frail mental patients was below the radar screen of most Americans. The fact that large percentages of them died as a consequence of transfer trauma was also not noticed by most people. (Douglass, 1984; Wood, 2002). In part, however, due to the sorry state of affairs with this new industry the condition of nursing homes was given close examination by the U.S. Congress and found to be wanting, which came to public attention with the publication of Nursing Home Care in the United States: Failure in Public Policy in 1974 by the U.S. Senate Special Committee on Aging (U.S. Senate, 1974). With the completion of a series of Congressional inquiries, the passage of the Older Americans Act, as amended in 1974, and other sentinel events of relevance, the nursing home industry came away from the 1960's under a cloud of public dissatisfaction and suspicion. One of the underlying reasons for the passage of the Older Americans Act was explicitly to prevent nursing home placements.

The elderly, frail, and isolated, poor from throughout the Metropolitan Detroit urban area are at risk of nursing home placement as Medicaid dependents, if family members have left the community or died, and if their assets are insufficient to be converted into long-term care in a private-pay bed. Out-migration of middle-aged and middle class African American Detroiters has increased during the last 30 years while most often the elderly family members remain in the City until physical health, poverty, or a serious hospitalization require consideration of a nursing home placement. Adult children who usually include fully employed men and women, may want to place their parent in a facility closer to where they now live. This pattern is not apparent in reverse where adults who move into Detroit then could move their aged dependent closer to them. As noted by many authors referenced above, especially Angelleli and colleagues, when a cycle begins that forces facilities to admit larger numbers of mentally ill patients, the desirability of the facility as a place of choice and for private pay is greatly diminished. This makes the facility even more dependent on mentally ill placements to sustain occupancy.

The first generation of facilities from the late 1950's and 1960's now constitute the core of the physical plants of most urban nursing homes. This is clearly true in Detroit. Such aging facilities face the high costs of heating, cooling, cleaning, and other routine maintenance and operations expenses that are far more efficient in newer facilities. Costs exceed revenues from Medicaid, and there is increasing pressure to extend services well beyond the model of long-term geriatric care to caring for many kinds of adult disabilities, mental illness, and chronic conditions, including late-stage HIV disease.

Because nursing homes that are certified for Medicaid in Detroit often have empty beds in recent years, due to a shrinking population and alternatives to nursing home placements (as part of a national trend), when a Medicaid recipient becomes available it is not in the facility's best interests to decline the admission unless the patient poses a serious threat or a care-obligation that the facility cannot provide. As a result, hundreds of mentally ill adults, who have activity levels, behaviors and personal needs that do not fit the traditional "old folks home" paradigm, now share Detroit's Medicaid facilities with traditional, frail elderly residents. The growing burden of Medicaid's various dependent populations can present a clinical case-mix within a nursing home that is very challenging; ranging from very frail and old, bedfast, various types and stages of dementia, disabled and mentally ill younger adults. The Direct Care Alliance called attention to this challenge in February 2004 (Donar, et al. 2004).

The organizational distribution of nursing homes includes several distinct and significant categories: Not-for-Profit, charitable-affiliates; For-Profit franchise; For-Profit group managed;

For-Profit stand-alone. Not-for-profit facilities in Michigan and throughout the United States are less likely to have large numbers of governmental inspection deficiencies than for-profit facilities. However, the literature and public impression is that this is a causal relationship that stems from perceptions of greed and exploitation or diversion of resources to owners and stockholders. An alternative explanation is clearly that especially in urban centers like Detroit the degree of difficulty in all aspects of the operation is far greater for the for-profit, Medicaid-dependent facilities than it is for the not-for-profits or the suburban facilities. This is especially true when it is recognized that multiple venues of care, and a financially healthy mixture of Medicare (skilled care) beds, and private pay beds with Medicaid beds permit the organization to provide care despite insufficient revenues from Medicaid. This set of circumstances is far more common in suburban areas of the Metropolitan Detroit market than in the City of Detroit.

As noted by Mor and colleagues (2004), there is a two tier system of nursing home care in the United States with the "haves" represented by both not-for-profit and for-profit facilities that have substantial proportions (or exclusively) private pay beds, Medicare-supported skilled care beds, multiple affiliated venues of care and basic beds that are resourced by both private pay and Medicaid. The "haves", in addition, serve a nearly homogeneous, traditional, elderly population that actually ranges from ambulatory and independent in terms of ADL to hospice. The "have nots", however, are nearly all predominantly Medicaid-dependent. The populations that they serve are predominantly poor. Populations served by the have-nots are far more likely to include large proportions of mentally ill, formerly institutionalized, and younger adults in a clinical case mix that is more challenging in many ways than a traditional, frail elderly population.

METHODS

A series of structured focus discussions was conducted during the summer, 2004 with samples of nursing home owners, administrators, and senior staff from facilities that are dependent on Medicaid for 85% or more of their residents as a source of revenue. This is our operating definition of "Medicaid-Dependent". Four group focus discussions were conducted between August and September 2004 that included 39 individuals from 11 independent facilities or nursing home chains. This represents approximately one third of the Medicaid-dependent facilities that serve the Detroit Area Agency on Aging's market. In addition, because several sampled individuals were not able to attend the group focus discussions, individual interviews were conducted with nine additional administrators, one owner and the corporate lawyer for one management firm. The focus discussions lasted approximately three hours while individual interviews lasted an average of two hours. Participants were afforded full human subjects informed consent protocol under the institutional supervision of the Human Subjects Review Committee (IRB) of Eastern Michigan University, from which permission to initiate field data collection was provided at the end of July 2004. All of these discussions and interviews were conducted under the same informed consent protocol. In addition, all participants were paid a small honorarium as compensation for their time. Focus discussions were tape-recorded, and reviewed for topic frequencies, technical substance, and sorted by subject area. These qualitative data were assembled and then paired to topic-specific conclusions from the published literature.

FINDINGS

Based on the very few relevant research reports in the published literature that deal exclusively with Medicaid-dependent facilities, the challenges faced by Detroit's nursing homes are similar to facilities in other major metropolitan areas. Participants reported that a majority of residents have few if any family members, close friends or others who visit on a regular basis. The majority of patients are African American, however very frail and isolated elderly residents are often White. These facilities, at the present time, are struggling to survive. Several

administrators told the groups that their facility was a major employer in the community. The owners and administrators indicated that their mission was not only to provide care for the patients, but also to continue to provide jobs and income to the communities in which they operate.

All but one of the facilities that were represented in the focus discussions were for-profit business. One was part of a chain of facilities; four were mutually owned and benefited from corporate and administrative assistance from a management company. The single owner/operator administrators frequently reported that their work was overwhelmed by interactions with families, government regulatory offices, the Medicaid authorities, and distractions from the "business of caring for people". It was noted that those facilities with "administrative depth" whose administrators could turn to specialists within their corporate system for financial, legal, or other support were more able to focus on management issues within the facility.

The Medicaid populations served in Detroit's nursing homes are highly case-mixed as a clinical distinction and rarely represent the traditional, homogeneously elderly patients with both Medicare and Medicaid clinical eligibility. Mentally-ill, developmentally disabled, or younger chronically ill adults with diagnoses such as Multiple Sclerosis, Parkinson's Disease, HIV-AIDS and other conditions that afflict a wide age-range of adults are often a large proportion of these nursing homes' resident populations. The focus discussion participants indicated that because of these clinical case-mixes the needs of residents are highly variable as well as the technical and training needs of the nursing staff. Staffs in such facilities are unable to focus on geriatric needs as they might have been trained to do in a nursing home because a large proportion of their patients do not have geriatric problems. The significant presence of ambulatory, mentally ill residents creates a number of problems and complications within the context of a nursing home.

Liability issues, too, increase when patients use or abuse alcohol or drugs. Visitors and family members supply some patients with alcohol and/or illicit drugs. This has been previously noted in S.E. Michigan (Douglass, 1980, 1981, Douglass, et al., 1982), however today the problem is exacerbated with substance abuse among younger and more ambulatory patients who share space with the frail elderly. When asked if family members brought alcoholic beverages into the facility covertly, an administrator responded, "How did you know?"

The clinical case-mix, alone, was reported to present significant challenges for nursing care planning, as well as all other services within such facilities. It is not unusual or uncommon for very frail elderly to share hall space, eating facilities, and recreational space with mentally ill adults. Recent management and psychological literature suggests that performance levels can be negatively affected with too much distraction beyond the "channel capacity". Minimally compensated nursing aides, who might be highly qualified for either geriatric care, or care of developmentally disabled adults, or for the younger adult mentally ill, or for persons with advanced HIV disease may not be able to handle the simultaneous complexity of having all of these conditions "on the floor" at the same time. Participants told us that finding appropriate training materials, avoiding staff burnout and recruiting new staff to work in a facility with this complex clinical case mix was very difficult. This case mix issue was raised by every participant (100%) and was always cast in the image of a degree of difficulty beyond the expectations of most people who work in long-term care. The administrators also indicated that with declining market demand from "traditional aged, frail patients", any empty beds needed to be filled or the financial crisis that most of these facilities would face would be overwhelming. One advocate also gave a prognosis of the situation by describing many facilities as being on "a slow slide to financial collapse, and dependent upon admissions of the mentally ill for short-term survival."

When asked about the problems that they face, and worry about, every day the participants were nearly of a single voice. A chronic shortage of registered nurses with appropriate training, qualified nurse aides, absenteeism and turnover of existing staff, and the need to, "begin the day by finding out how many staff 'called in' overnight" were issues that dominated the daily routine of these administrators, senior staff and owners. The participants also indicated that the local infrastructures were not helpful in staff retention because a shortage of safe and secure parking for staff's automobiles, lack of predictable mass transit for staff who could not afford to purchase their own vehicle, and other problems made the shortages of staff even more difficult to resolve.

The inadequacy of Medicaid reimbursement was the most frequently noted causal issue from all focus discussion participants. This is clearly a bottom-line issue that has precipitated many recent nursing home failures. Medicaid reimbursement rates are set annually, based on reports to the State every year. According to this study's respondents, however, increased reimbursement may not be implemented for as long as two years subsequent to reporting that costs have increased. Participants reported that it is very difficult to anticipate costs two years in advance and still be consistent with the requirement to report only true costs based on the most recent year's experience. Unanticipated expenses, which are common in older building stock, can wreck an administrator's budget and spending plan. Reliance on Medicaid revenues may offer little or no slack with which to initiate essential repairs and maintenance. Failure to initiate such repairs will lead to regulatory tickets and more unanticipated expenses. Facilities with little commercial credit, no profit centers beyond the Medicaid beds, and with ongoing debt, face a nearly impossible task to keep up with cost increases, competitive salaries for nursing staff, or even to respond to routine economic inflation with fixed Medicaid reimbursement rates.

When facilities have clinical case mixtures that include younger, mentally-ill residents; this may lead to lower Medicaid reimbursement rates. Although younger, active, mentally-ill residents have fewer or less costly medications and medical procedures, such patients are often more labor-intensive for the staff and, therefore, actually more expensive to care-for than many frail elderly patients. An administrator reported that, "...the need to accept younger patients has completely changed the job. What I really do is run a small mental hospital; I just happen to have a lot of needy old people too."

Medicaid applications on behalf of patients, even immediately after a hospitalization, can require months to process for approval. Facilities are expected to absorb the cost of care for such "pending" cases until the Medicaid approval is provided. For independent facilities with no corporate depth, this can be a major crisis.

DISCUSSION

The participants of focus discussions and those who were individually interviewed were highly motivated, experienced, and reflected a sense of near-desperation regarding the degree of difficulty that is present in the Medicaid-dependent nursing homes. In these discussions it was recognized that good management within the continuum of care for the most vulnerable people requires stability and continuity of staff and also administration. It was reported in every discussion that managerial turnover, dealing with the lack of qualified, licensed and willing replacement administrators, and then convincing them to take the job is as much of a challenge as is the widely recognized nursing shortages that all health care facilities face. The higher the dependence upon Medicaid and the greater the clinical case-mix of traditional, frail elderly with mentally ill and other categories of disabled adults, the greater the frequency of administrative (and ownership) turnover among nursing homes. These findings are consistent with several studies of nursing home administrator work satisfaction and turnover (Murphy, 2004; Singh and Schwab, 1998).

Our thesis here is that Medicaid-dependent facilities are largely under-resourced and face a daunting task that would not be acceptable in more financially independent and well-resourced environments. Medicaid-dependent nursing homes have been financially distressed for over 30 years due to persistent increases in costs of facility management, staffing and building maintenance, medical care cost inflation, general inflation of salaries and minimum wage, and increased licensing expectations of the State. At the same time, the willingness or ability of the State of Michigan, along with most other states, to increase Medicaid reimbursement has suffered from legislative hesitation to sustain the Program in a way that counteracts these elements of normal and predictable cost increase.

Being financially dependent upon Medicaid has had many consequences for these facilities that are nearly all negative. These facilities serve populations defined by the patient's financial poverty instead of by the clinical presentation of the patient. Because of this and because of the closure of alternative institutions for the mentally ill, Medicaid-dependent nursing homes have become "dumping grounds" for the mentally ill who cannot manage their own affairs in more independent living circumstances. In addition, population losses in Detroit have reduced the demand for traditional nursing home care, leaving empty bed space that is available for patients other than the traditional, frail, elderly. In combination, such events have forced a clinical casemix within the facilities that is far from the traditional image of a nursing home. This has increased the degree of difficulty for the management and caregivers within these facilities. The age, gender, and diagnostic combinations of patients that are faced by Detroit's Medicaid-dependent facilities present a degree of difficulty that is simply unacceptable if consistent, highly regulated, and high quality care is expected for any of these vulnerable populations.

One of the questions that initiated this project was that of how many nursing home beds does PSA1A need? If these facilities only served the elderly, frail, then Detroit and PSA 1A would have far more capacity than current demand requires. The clinical case mix, however, and the demands of a Medicaid Program that serves vulnerable adults on the basis of poverty status and not based on age, frailty, or other clinical determinants diminishes the ability of these facilities to consistently employ standards of care for age-segregated facilities as would be expected in a facility that only served the frail elderly. Nursing homes within PSA 1A that are largely Medicaid-dependent are needed because of a variety of human needs that greatly exceeds demands from the elderly market, alone. Statistical predictions of demand that are created on the basis of projections of aged population growth, without serious consideration to issues of poverty, out-migration of younger family members, urban development, transportation patterns for visitation as well as for employment, and other salient issues will give a false sense of expected demand in some areas.

We conclude from this that the stakeholders in public health, aging, mental illness, urban development, and health care are very reluctant to give the owners, administrators and staff of Medicaid-dependent nursing homes the credit they deserve, nor the financial resources that are needed, to do a job that the rest of us don't want to do ourselves. We as a larger society seem to punish this under recognized and poorly resourced enterprise for not doing a better job while simultaneously withholding the resources that we, ourselves, would probably require. Because of the situation with widespread poverty, deinstitutionalized mental patients, and unknown numbers of isolated elderly residents of PSA 1A (and elsewhere) who may soon be at risk of requiring some form or duration of nursing home care, the need for these facilities to succeed is in the best interests of the entire community, and the State of Michigan.

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Ethical Dilemmas in Publishing a Journal of Public Health Practice

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Publication is a gateway where an ethics checkpoint can be established. Institutional Review Boards (IRB) and Ethics Review Committees at academic institutions and medical facilities grant prior approval for and then monitor biomedical and behavioral research involving human subjects, primarily to minimize or avoid ethical problems. The end product of research is generally the dissemination of findings in a professional journal. Journals, then, can provide additional ethical safeguards after the research has been completed (Creinin and Shields, 2005). Editors and editorial boards of most scientific and professional journals have been willing to assume the role of voluntary, that is, non-governmental gatekeeper and enforcer of federal guidelines for the protection of human subjects.

While publishing both research and practice findings is essential to improving the health and well-being of individuals and society, human subjects participating in both health and behavioral research and public health practice have a right to privacy that should not be breached. Public health authorities have a long history of respecting the confidentiality of public health records, data, and other information. The majority of states as well as the federal government have laws that govern the use of, and serve to protect, identifiable information collected by public health authorities (MMWR, 2003) .

The International Committee of Medical Journal Editors Uniform Requirements for Manuscripts states that:

Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt (ICMJE, 2006).

Many journals perform this ethics check by requiring authors to either affirm or submit documentation that their project received prior review and approval from an Institutional Review Board or Ethics Review Committee. This ethics check, however, varies greatly from journal to journal and by research area. While over 500 journals have adopted the Uniform Requirements, Amdur and Biddle (1997) found that less than half (47%) required IRB approval for studies involving human subjects as a prerequisite for publication. In addition, the journal *Pediatrics* reported that 97 percent of randomized, clinical trials claimed IRB approval, compared with 70

percent of prospective cohort studies, 37 percent of retrospective cohort studies, but only 9 percent of large dataset analyses (Bauchner, 2002).

These findings reflect the distinction between research and practice. The *Belmont Report*, written by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (National Commission, 1979) identified the three ethical principles of respect for persons, beneficence and justice, and defined the boundary between biomedical and behavioral research and the accepted and routine practice of medicine. Practice was defined as interventions designed solely to improve the well being of an individual patient or client while research was to test a hypothesis and contribute to generalizable knowledge. The *Belmont Report* held that if any element of research is present in an activity, that activity should undergo review for the protection of human subjects. These recommendations were incorporated into federal regulations known as the *Common Rule (45 CFR 46)*.

It is quite clear that most existing medical and research codes fail to take public health into account (Kass, 2001). The National Commission did not have any members directly involved in public health, and neither the *Belmont Report* (National Commission, 1979) or Levine's (1978a, 1978b) two commissioned background papers mention public health or epidemiology. This placed public health in a sort of ethical limbo. Two issues need to be addressed: first, how to distinguish public health research, which requires IRB approval, from public health practice which does not always require IRB approval, and second, how to reconcile regulations designed to protect individuals with the need to protect communities and populations.

DISTINGUISHING PUBLIC HEALTH RESEARCH AND PRACTICE

Defining the boundary between public health research and practice is problematic (Burris, Buehler and Lazarini, 2003). In his background paper for the *Belmont Report*, Levine (1978a) briefly explored the boundaries between the research activities and professional practices of social scientists. Epidemiology is not mentioned, and Levine (1978a:23), almost as an afterthought, wonders whether it is to society that we ought to offer the opportunity to give informed consent. State authorization is surely the equivalent of societal informed consent, and society has created, tasked and financed public health research and practice.

Public health practice is authorized and governed primarily by state rather than federal laws that require health departments and agencies to systematically collect data for surveillance, disease control and prevention, and program development and evaluation (MacQueen and Buehler, 2004). Since these practice-based activities are also carried out by researchers, it may be difficult to determine which public health activities constitute research and which represent public health practice, or when practice activities evolve into research activities.

In January 1999, the Director, Division of Human Subject Protections, Office for Protection from Research Risks (OPRR) issued a memo (Puglisi, 1999) requiring each institution engaged in human subjects research to provide OPRR with a satisfactory Assurance to comply with the federal regulations at *45 CFR 46.101(b)*. In response, the Centers for Disease Control and Prevention prepared *Defining Public Health Research and Public Health Non-Research* (Speers, 1999). This document stated that the federal regulations or *Common Rule (45 CFR 46)* did not directly address many public health activities and did not recognize the statutory authority of state and local health departments to conduct public health activities using methods similar to those used by researchers. This meant that the human subject protections applicable for activities occurring at the boundary between public health research and non-research (practice) were not readily interpretable from the regulations.

The document claimed that CDC could decide what research was and whether the Federal regulations were applicable, although final determination ultimately rested with the Office for Protection from Research Risks (OPRR). The CDC wanted to provide guidance to state and local health departments and other institutions that conduct research with CDC staff or were recipients of CDC funds. But it did not describe how this collaboration would be achieved or how the ethical guidelines would be adopted or even recognized by the IRBs of various CDC partners including universities and health/hospital systems.

The CDC document (Speers, 1999) asserted that what distinguished research from non-research (practice) was the primary intent or, in the words of the regulations, the design of the activity. Levine (1978a) first identified the importance of intent when he recognized that clinical research involved a set of complex activities some of which may be administered for therapeutic purposes, while other procedures were undertaken solely to answer a scientific question. Weijer (2001) explained that therapeutic procedures, that is medical practices, are justified by their potential to benefit the subject, while non-therapeutic procedures, that is research, are justified by their potential to generate knowledge. He agreed that the difference in intent is what is morally relevant.

But the CDC (Speers, 1999) then goes on to assert that the primary intent of non-research (practice) in public health is to protect the health of the population through such activities as disease surveillance, prevention, or control. Non-research activities systematically gather information designed to benefit a specific community, although occasionally they may provide unintended generalizable benefits to others by, for example, preventing the spread of a disease to other vulnerable populations (MMWR, 2003). Knowledge generated by such non-research activities does not extend beyond the scope of the activity.

Furthermore, CDC argued that even if a non-research project may produce generalizable knowledge after the project is completed, the initial non-research classification remains in force. But if subsequent analysis is undertaken that involves gathering or using identifiable private information to generate or contribute to generalizable knowledge, then the analysis constitutes human subjects research and requires IRB review. Finally, if a project includes multiple components and at least one of those components is designed to generate generalizable knowledge, then the entire project is classified as research unless the components are separable.

The CDC (Speers, 1999) also stated that publication or dissemination of findings do not necessarily differentiate research from non-research. From an ethics perspective, information collected through public health practice falls under the HIPAA Privacy Rule (Standards for Privacy of Individually Identifiable Health Information) which expressly permits certain information to be shared for specified public health purposes. For example, some information may be disclosed without individual authorization to a public health authority legally authorized to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability [45 CFR § 164.512(b)]. Further, the Privacy Rule permits covered entities to make disclosures that are legally required for public health purposes (MMWR, 2003). This differs substantially from the Institute of Medicine's (IOM, 2000) research focused approach to publication *Protecting Data Privacy in Health Services Research*, which suggested that if the intent or possible intent of the investigator is publication, then the project represents research and IRB approval is necessary.

Table 1: CDC Distinctions between Research and Practice (Non-Research)

	Research	Practice (Non-Research)
Definition	“...systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.” (ref. 45 CFR 46)	May use scientific methods to identify and control a health problem with benefits for the study participants or their communities.
Primary Intent	To generate new or generalizable knowledge (information that can be applied in other settings)	To benefit study participants or the communities from which they come
Methodology	Scientific principles and methods used. Hypothesis testing/generating Knowledge is generalizable	Scientific principles and methods may be used. Hypothesis testing/generating Knowledge may be generalizable
Examples		
Surveillance Projects	Scope of data is broad Analytic analyses Hypothesis testing Subsequent studies using cases	Regular, ongoing collection and analyses to measure occurrence of health problem (disease registry) Scope of data is health condition or disease, demographics, and known risk factors Invokes public health mechanisms to prevent or control disease or injury
Emergency Response	Samples stored for future use Additional analyses performed beyond immediate problem Investigational drugs tested	Solves an immediate health problem No testing of methods or interventions
Program Evaluation	Test an intervention Systematic comparison of standard and nonstandard interventions	Assess success of established intervention Evaluation information used for feedback into program (management)

Defining Public Health Research and Public Health Non-Research (Speers, 1999) contained a table that compared research and practice (or non-research) in terms of definition,

primary intent, and methodology, as well as providing examples of each for surveillance, emergency response and program evaluation. As already mentioned, a key difference is in intent and not in methods used. The main distinction appears to be that research involves additional data collection using cases (surveillance) or investigational drug testing (emergency response) or systematic comparisons of standard and non standard interventions (program evaluation) that goes beyond the regular, routine collection and analyses of data related to known risk factors or the immediate health problem or program under study.

PROTECTING COMMUNITIES AND POPULATIONS

Four basic principles—autonomy, dignity, integrity, and vulnerability—are offered as a simple, accessible, and culturally neutral approach to thinking about ethical issues in health care (Gillon, 1994). But Levine (1982) asked whether such principles are universal valid standards or if some degree of cultural relativism should be accepted, permitting each culture to decide how it should show respect for its own members. Weijer (1999) concluded that the only way to take community into account was to propose a new ethical principle which he called ‘Respect for Communities.’ This principle acknowledges that the community has rights and interests separate from those granted to individual community members.

Weijer and Miller (2004) argued that people generally identify themselves as members of one or more communities that help form their values and self-understanding. Furthermore, many communities possess the authority to make binding decisions on behalf of individual members and can legitimately curtail individual liberty and free will in certain situations. They also recognized that the primacy of the individual versus the community varies from one community and culture to another. In particular, individual rights and liberties are held in high esteem in western liberal nations, but that is not the case in many non-Western nations and in certain groups such as Native American communities.

In a discussion of ethics and public health, Callahan and Jennings (2002) noted the tension between the orientation towards individual liberties and autonomy found in the bioethics literature, regulations, and guidelines on the one hand, and the interests of public health to limit the freedom of the individual for the sake of (a) his or her own greater good or best interests or (b) the common good or public interest. They asked whether the bioethical research model focused on individual informed consent and tightly regulated studies of human subjects at risk of exploitation is an appropriate model for public health research that may either pose no medical or other risks to the individual or make consent impractical to gain in research encompassing large communities.

The *Belmont Report* does not mention the word community at all, and the *Common Rule* (45 CFR 46) does not focus on communities *per se* although it is highly concerned with vulnerable groups—the mentally ill, children, etc. (Levine, 1988, Weijer, Goldsand and Emanuel, 1999). Levine (1978a:24), however, mentioned that the community, of which the subject is a member, is also put at risk as the social scientist uses the information in his publications or as the basis of his consultative opinion leading to formation of public policy. Note that public health is conspicuous by its absence or is lumped in with the social sciences.

On the other hand, *The International Guidelines for Ethical Review of Epidemiological Studies* (CIOMS, 1991) attempted to apply general ethical principles at the community or population level, that is, how one community related to another, and how a community treated each of its members and members of other groups with different cultural values. Specifically the

Guidelines stated that investigators must respect the ethical standards of their own countries and the cultural expectations of the societies in which epidemiological studies are undertaken.

The *Guidelines* then recommend that when individual informed consent cannot be obtained, community agreement may be sought from a community representative and, if the study is objectionable to the community, individual informed consent may not be sufficient to render a study ethical. Whenever possible, investigators should not expose groups to harm, including the harm of disruption of social mores. Where findings could be applied in public health measures to improve community health, they should be communicated to the health authorities and be publicized in the community by whatever suitable means are available.

The *Guidelines* warned epidemiologists against bringing disadvantage to communities or transgressing their values. Although cultural values and social mores must be respected, the *Guidelines* noted that the purpose of an epidemiological study may be to stimulate change in certain customs or conventional behaviors that would hopefully improve the health and wellbeing of the community and its members, for instance, with regard to diet or a hazardous occupation. Epidemiological studies may inadvertently expose groups to harm. When the location or specific circumstances of a study are important to understanding the results, care should be taken to protect the confidentiality of respondents and the community itself.

A more serious problem may emerge when telling the truth and openly disclosing scientific findings are opposed by certain community leaders or interest groups, or could lead to economic loss or withdrawal of health and other services. This may depend on how the data is presented and interpreted, that is, the style and tone of the report or publication should avoid adverse or moral criticism and be discrete in communicating and explaining the findings. Weijer and Emanuel (2000) suggested that if agreement between researchers and the community representatives cannot be attained within a reasonable amount of time, the competing interpretations of the study should both be published.

CONCLUSION

Scientific journals have been assigned an after the fact policing role in the enforcement of human research protections. This is a form of self-censorship and suppression of scientific knowledge which reflects social, political, and cultural pressures on what is studied, how studies are performed, how data are interpreted, and how results are disseminated (Kempner, Perlis, Merz, 2005). This can include refusing to publish material that might be detrimental to national security or studies that obtained data through unacceptable means, such as experiments that harm humans.

Public health journals face a challenge in supporting human research protections. The journals clearly need to distinguish between research and non-research or practice articles. Weijer (1999) thought that a reasonable formulation of the principle of respect for communities conferred on the researcher an obligation to respect the values and interests of the community in research and, wherever possible, to protect the community from harm. By extension, this suggests that public health journals should develop a set of guidelines for publication that encompass respect for communities.

Institutional Review Boards (IRBs) do not routinely consider the benefits and risks to communities or populations. Further IRBs may not recognize that the collection of data for surveillance, disease control and prevention, and program development and evaluation may be legally mandated, covered by the HIPAA privacy rule, or be eligible for a waiver or qualify as exempt from informed consent. Public health journals should not require that all authors obtain

IRB approval in order to be published since some articles concern practice not research. The journals, however, should require documentation that funding agencies or data sources have released the data or made it public, and that the data collecting process observed the HIPAA Privacy Rules in obtaining the information for publication.

Journals should be more proactive through editorial policies. Journals should alert reviewers to the possibility, however remote, that data can be falsified and to check that the work has proper and sufficient references and citations to avoid charges of plagiarism. Editors should ensure that the tone of the article is respectful and not inflammatory or prejudicial. Many journals and government publications will not identify smaller governmental subdivisions and will not publish data in a cell that contains less than 50 respondents or subjects, especially if they are members of a minority group or vulnerable population. In case studies and program evaluations, journals should not publish names or otherwise link an individual to a specific data item and should carefully consider whether a community should be identified or a pseudonym used.

Of course the editor, editorial board, and peer reviewers can and should decide which section of the journal they think is appropriate for a manuscript. Certainly peer review and publication involves many of the same questions that IRBs ask: what were the methods used to recruit or select subjects, were reliable and valid scientific methods used, was the data collected in a way that protected privacy, does the manuscript protect the identities of individual subjects and communities when appropriate. But journals should maintain their independence, meaning they should not rely solely on IRB decisions or automatically enforce them after the fact.

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