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Trust And A Respect For Persons: Public Health As A Profession Of Relationships

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Trust and a Respect for Persons: Public Health as a Profession of Relationships

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Abstract

The purpose of this thesis is to explore the concept of empathy, or "the ability to share someone else's feelings,[1]" in public health, examining the concept's effect on both the ethical mandates of the profession and the validity of community-engaged research results. The ethical guidelines of the profession, as outlined by the American Public Health Association and other prominent public health researchers, were used to inform such an exploration, as was personal experience and Yale public health researcher insights. A case study of homelessness public health research was conducted. Interviews and surveys were conducted with prominent homelessness community advocates with public health experience, a public health researcher, and a formerly homeless individual with prior research experience..

The thesis's exploration of empathy revealed many insights in regards to its importance in public health practice, as well as the differences between empathy and a simple understanding of populations and research participants. Interviews revealed that public health research performed using empathetic community engagement techniques led to more valid, applicable study results that were effective. Empathetic research practice allows for researchers to truly wrestle with and comprehend the real concerns and problems of the research participants, and this comprehension leads to research that is participant-driven, with results that are actually applicable to the community's needs. Although this initial work has been done to investigate the importance of community-engaged public health research that is directed by empathy, it is important to continue this work, relying on work

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[1] "Definition of Empathy." *Merriam-Webster Dictionary.* Web.

qualitative researchers already do in regards to engaging with populations they are

studying and performing research with individual and community stories in mind.

Table of Contents

Table Listing

People. Stories. Relationships. Although public health is essentially a population-based science, concerned with high-level practice and groups of individuals, these three items still remain at the heart of the profession. Public health research is concerned with improving the health of populations, but these populations consist of individuals, all with stories and ties to one another. In working with the population, public health researchers are working with individuals, whether directly or indirectly. As an illustration of such a view, this paper seeks to illustrate the centrality of empathy and perspective-taking in public health, specifically community-based public health research. Empathy is defined as "The ability to share someone else's feelings,[2]" and perspective-taking is defined as "viewing a situation or understanding of a concept from another's point of view.[3]" These terms, normally used to describe the practice of medicine, are not exclusive to that discipline, and can be translated into public health language to inform such research, linking with such concepts as trust and a respect for persons. This translatability is evident in public health homelessness research. Informed by interviews with community leaders, as well as the existing literature on public health ethics and community-based participatory research (CBPR), I propose that genuine relationships built on mutual trust and exchange are essential to public health research, allowing such research to have a real effect on populations and the individuals they consist of.

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[2] "Definition of Empathy." *Merriam-Webster Dictionary*. Web.
[3] Galinsky, A., Maddux, W., Gilin, D., & White, J. (2008). Why it pays to get inside the head of your opponent. Psychological Science, 19(4), 378-384. doi: 10.1111/j.1467-9280.2008.02096.x

In this paper, I address the question of empathy and search for evidence that empathy enables more effective public health research. My objective is to explore and better understand the role an empathetic approach plays in understanding and providing valid, actionable results that positively affect populations taking part in such research. Throughout my two years of training as a Yale School of Public Health student, I have yet to come across the concept of empathy in any course, and in speaking with a Yale public health researcher with over twenty years of public health research experience, such a dearth became even more evident. In all of the conferences and research meetings the researcher has been present at, not once have empathy and public health been mentioned together. I assert that empathy is an essential concept to consider in public health research, and is a key aspect of both the promotion of human dignity and ensuring study validity, both important public health concepts that will be discussed later.

Background - Trust and a Respect for Persons: Public Health Ethics

Public Health Ethics: Why it Matters

Public health, according to John Last's entry in *The Dictionary of Public Health,* is "an organized activity of society to promote, protect, improve, and, when necessary, restore the health of individuals, specified groups, or the entire population."[4] In order to develop a framework for examining person-centered themes in public health research, it is necessary to first understand the necessity and development of public health ethics as its own entity, separate from other areas of health. Various frameworks have been proposed to guide public health research,

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[4] Last, JM, (editor). A Dictionary of Public Health. New York, NY: Oxford University Press; 2006.

and all are useful in informing an integrated and person-centered approach to the practice[5,6,7].

Public health has been increasingly concerned with ethically codifying guidelines for both research and practice. Such efforts began in earnest in the late 1990s, with the recognition that public health needed its own ethical theory, separate from bioethics and medical practice, as public health has the fundamental difference of caring for communities, rather than focusing on individuals.[8] In addition, the fact that public health researchers and practitioners intervene in communities in which they do not have personal relationships (usually) is an important point for discussion, as it is a major concern of public health ethics and a target for proposed intervention in the state of traditional public health research.

There is an inherent collective vs. individual difference between public health and medicine, with the former being primarily concerned with population health and the latter being primarily concerned with the health of individuals. In addition to this, there also exists the diversity of roles in public health research. Although there are various roles (such as nurses and physicians), all actors are focused on delivering direct care. Public health researchers and practitioners are focused on using non-medical means to prevent disease and promote health. A public health research team may include epidemiologists, statisticians, economists,

[5] Beauchamp DE. The Health of the Republic: Epidemics, Medicine and Moralism as Challenges to Democracy. Philadelphia, PA: Temple University Press; 1988.
[6] Swain GR, Burns KA, Etkind P. Preparedness: medical ethics versus public health ethics. J Public Health Manag Pract. 2008;14:354-7.
[7] Lee LM. Public Health Ethics Theory: Review and Path to Convergence. Public Health Reviews, Vol. 34, No 1. 2012.
[8] Verweij M, Dawson A. The meaning of 'public' in public health. In: Dawson A, Verweij M, (editors). Ethics, Prevention, and Public Health. New York, NY: Oxford University Press; 2007.

policymakers, and behavioral scientists, to name a few roles.[9] With this in mind, it is necessary to have a professional ethics code for public health that informs research in ways that all team members can understand. In addition, as will be discussed later, it is important for all members to be informed as to the impact the research will have on the community, with the community's needs in mind.

Along with the differing roles in public health, there also exists two main schools of thought when it comes to public health research: quantitative and qualitative. Quantitative public health research is more numbers-driven, with data and epidemiology at the heart of analysis. Qualitative public health research is focused more on personal interactions, stories, and community knowledge. This school focuses on the idea that learning and results are superficial without a deeper knowledge of the population, as built through relationships or, at the very least, some appreciation for community stories. Qualitative researchers may question the relevance of findings without such an involved approach, and the concept of empathy in public health, which will be introduced later in more depth, may already be familiar to them, thanks to this relationship-driven approach.[10]

Although various reports on public health ethics see clinical and bioethics as unique from public health ethics, both ethical frameworks can be used and transferred to public health ethics, albeit with modification. Public health ethics, as stated, is a framework concerned with care for populations. Dean Beauchamp's work in 1988 foreshadowed future projects that would take place, establishing

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[9] Tauber AI. Medicine, public health, and the ethics of rationing. Perspect Biol Med. 2002;45:16-30.
[10] Baum, Fran. "Researching Public Health: Behind the Qualitative-quantitative Methodological Debate." *Social Science & Medicine* (1995): 459-68. Web.

public health ethics as concerned with balancing individual needs and community well-being.[11] In establishing the individual as an important piece of this balance, Beauchamp allowed for an exchange between the worlds of clinical and public health ethics, and this was taken further in the 1990s and 2000s. This inclusion of concepts related to individuals, such as empathy and individual interactions, in public health paved the way for a new type of community engagement. In addition, the recognition of respecting and promoting human dignity is of great import to public health ethics. Promoting human dignity means recognizing the inherent worth and capabilities of a human being, respecting the individual's needs, desires, and capabilities. This concept maps onto empathy well, in that both focus on an appreciation for the "other" as an equal in relationships, acknowledging the other's story and perspective as valid and important to consider.[12]

The Ethics of Public Health: A Discipline's Guiding Light

Although various public health ethics frameworks have departed from the traditional clinical ethics approach, the American Public Health Association (APHA) has maintained a translatability between the two codes, holding relationships as important for public health. In 2010, APHA published its "10 Essential Public Health Services." Item four of this list is "Mobilize community partnerships to identify and solve health problems," implying a need for strong, trusting relationships between public health researchers and the communities with which they are performing research. APHA's item calls for using "with," instead of "on," when referring to the

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[11] Beauchamp DE. The Health of the Republic: Epidemics, Medicine and Moralism as Challenges to Democracy. Philadelphia, PA: Temple University Press; 1988.

[12] [12] Buchanan D. Autonomy, Paternalism, and Justice: Ethical Priorities in Public Health. Am J. Public Health. 2008 January; 98(1): 15-21.

researched communities, as the partnership between researchers and the community is essential to public health that contributes to the good of the community. In addition, the fifth public health service listed is "Develop policies and plans that support individual and community health efforts," something impossible without researcher/community relationships built on trust and an understanding of community concerns through empathy and perspective-taking. Empathy entails an understanding of an individual's needs by actually sharing the individual's feelings, and perspective taking allows for the viewing of an issue from another's perspective. In terms of research, empathizing with and taking the perspective of a community member allows the researcher to understand the individual's true needs, and if the researcher develops empathetic relationships with a sufficient number of community members, he or she can understand the true nature of public health problems in the community, as seen by community members. Essential to effective public health research is this understanding of community concerns, and the APHA codifies this understanding as essential public health service numbers one and two: 1) Monitor health status to identify community health problems; 2) Diagnose and investigate health problems and health hazards in the community.[13]

With so much of the APHA's official aims ordered towards understanding community needs and creating fruitful relationships between researchers and the community, public health ethics has a clear connection with clinical and bioethics, as illustrated by physician and public health researcher Geoffrey Swain.[12] A logical

[13] American Public Health Association. 10 essential public health services. Available from URL: www.apha.org/about-apha/centers-and-programs/quality-improvement-initiatives/national-public-health-performance-standards-program/10-essential-public-health-services (accessed 17 November 2015)

prerequisite of the creation of fruitful community-researcher relations is the development of meaningful relationships on the individual level, which leaves room for empathy, a relationship-based concept. Swain proposed a public health ethics code with relationships and community needs as a paramount concern. His work built on Kass's 2001 framework, and informs public health research with its focus on community engagement.[14] Swain proposes a framework connecting clinical ethics with public health ethics, allowing for translatability between the two disciplines. In order to understand the ethical mandate of empathy in public health, as well as illustrate the concept in public health research, it is necessary to examine an actual area of research and interaction with the community at large. There is a dearth of discussion in regards to the concept of empathy in public health and its importance to both promoting the dignity of persons and preserving the validity of results, and this paper and the following case study begins to address this dearth.

A Public Health Case Study: Empathy in Homelessness Research

I used a case study approach to examine the importance of empathy in public health research. The APHA's guidelines serve as a guidepost for defining and integrating empathy into public health research, but what does this look like in practice? It is helpful to examine a specific public health issue, that of homelessness, to illustrate empathy in public health research. Although public health research, at large, relies on human participation at some level, whether it be through interview questions, surveys, or active engagement, homelessness research goes beyond such

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[14] Swain GR, Burns KA, Etkind P. Preparedness: medical ethics versus public health ethics. J Public Health Manag Pract. 2008;14:354-7.

participation, as researchers are interacting with individuals who are at their most vulnerable, given their homeless state. As members of society who have been marginalized, it is important, and even necessary, to develop trusting relationships based on mutual respect between researcher and study participant in order to collect valid results, as without this trust, the study participant might not provide candid and honest input. In addition, the ethical imperative to recognize the human dignity of all requires a genuinely relationship-driven approach to such research. Given this vulnerability and specific need beyond that of the general population, as similar to other vulnerable populations, such as undocumented immigrants and prison inmates, empathetic research practices are especially important. The homeless population's vulnerability stems from their lack of basic access to shelter and, in many cases, the financial means to purchase the basic necessities beyond shelter, which includes food and clothing. Public health homelessness research can be used as an illustrative area on which to build the foundation of what empathy means in public health. I will discuss the importance of empathy through examples, as illustrated later.

Investigating Homelessness Research: Methods

In order to better understand public health homelessness research and develop an idea of what it means to be an empathetic researcher, I conducted surveys and interviews. I surveyed and interviewed two local homelessness community leaders, surveyed a Yale School of Public Health researcher who has performed extensive community-based research, and surveyed and interviewed a formerly homeless New Havener. Three IRB-approved exempt survey/interview

instruments (one for each category: community leaders, researchers, and formerly homeless individuals) were developed to get at the heart of what empathy means in public health research, and what an empathetic public health researcher would look like.

The first set of interview questions was aimed at homelessness community leaders, and included the following questions: (1) What has been your experience, if any, with homelessness research/researchers? (2) According to medLexicon, empathy is "The ability to sense intellectually and emotionally the emotions, feelings, and reflections that another person is experiencing and to communicate that understanding to the person effectively." What would an empathetic public health homelessness researcher look like, and what would his/her research look like? (3) Do you see community engagement as a crucial part of homelessness research? If so, how have you seen this enacted (or not)? (4) What does your work with homelessness and the homeless community need most from a public health researcher?

The second set of interview questions was aimed at homelessness researchers, and included the following questions: (1) Throughout your research, what has been your experience, if any, with the term empathy? Is there a place for such a concept in public health research? (2) If answer is yes, what would an empathetic public health researcher look like, and what would his/her research look like? (3) How could the public health discipline focus more on empathy? Is this important for public health research? (4) What has your experience been, if any, with Community-Based Participatory Research (CBPR)? Do you see CBPR as a

possible move towards community-centered public health research? Do you see empathy as crucial to effective CBPR, and if so, how? (5) What does a community gain from public health research, and is this consistent throughout studies? Do you see public health research as designing studies based on community needs, or first considering research interests?

The third set of interview questions was aimed at formerly homeless individuals who had had previous experience with both homelessness researchers and advocates, and included the following questions: (1) Public health aims to prevent disease, promote health, and prolong life among the population as a whole. It differs from medicine in that it focuses on entire populations, not on individual patients. What has been your experience, if any, with public health research/researchers, and has it been positive or negative? (2) Empathy is the ability to feel what another person is feeling and act accordingly. What would an empathetic public health researcher look like, and what would his/her research look like? (3) In your research experiences, if any, have homelessness researchers shown empathy? Do you see the inclusion of formerly homeless and homeless individuals in the research process as important, and what role does empathy play in this? (4) In your opinion, what does the homeless community need most from public health researchers?

Interviews were ascertained via previously established relationships, both within Yale School of Public Health and through personal involvement in the greater New Haven community. In addition, a standard recruitment e-mail was sent out to community leaders, both of whom work closely with homeless and formerly

homeless individuals as part of a housing and homeless resources non-profit. Interview/survey answers were recorded on Qualtrics, and occurred either via self-reported Qualtrics response, in-person interview, or phone interview.

Results and Analysis

The Research Process

Interviews were ascertained with two community leaders, one researcher, and one formerly homeless individual. In addition, I had less formal conversations with homeless individuals whom I met through my participants.[15] Although the number of interviewees was small, the interviewees were all respected community members whose experience allowed for quality responses that could be used to roughly evaluate sentiments in regards to homelessness in New Haven. In addition, both community leaders and the formerly homeless individual are in regular contact with currently homeless and recovering formerly homeless individuals, and are invested in trusting relationships with members of the population. Both community leaders have decades of experience advocating for and enabling homelessness research, and one has a Yale-conferred Master of Public Health degree and has actually been involved in the homelessness research process through study design, facilitation, and participation. Both know New Haven's homelessness community, as well as the current homelessness research being performed, intimately, and have a deep understanding of both the political and social landscapes surrounding the issue. The researcher interviewed has dealt extensively in qualitative research, performing qualitative research investigating the effects of housing stress and

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[15] "Formerly Homeless Individual Interview." Personal interview. 22 Feb. 2016.

various issues surrounding housing and homelessness. The formerly homeless individual was homeless for years before seeking help from a community organization, and is in the process of developing a community outreach and support program for currently homeless individuals. All respondents are knowledgeable and in touch with the current state of both homelessness and homelessness research and policy, and provided deep insight into what empathy means in homelessness research.

Interviewee	Affiliation	Nature of Work
Community Leader 1	• Community non-profit serving homeless and formerly homeless individuals • Housing • Social Services • Master of Public Health	• Aids homeless and formerly homeless individuals in securing safe housing • Connects homeless to resources
Community Leader 2	• Community non-profit serving homeless and formerly homeless individuals • Homeless and at-risk women's support group leader	• Works with homeless and at-risk women in New Haven • Connects women to resources
Public Health Researcher	• Yale University PhD	• Focuses on qualitative, community-based work related to urban issues and housing • Studies issues related to neighborhood, place, and social stigma
Formerly Homeless Individual	• Intermittently homeless for five years • Homeless services organization founder	• Interacts daily with homeless community • Weekly programs to support and counsel homeless

Table 1: Participants Interviewed/Surveyed

Finding #1: Relationship-Driven Research is Crucial

Interviews revealed a picture of public health of which empathy and trust are integral (and even necessary) aspects. Interviews revealed the vulnerability of the homeless community. One community leader, with extensive and deeply-rooted relationships with homeless mothers and family members, said it best: "Researchers are asking these women to bear the most vulnerable aspects of their lives, sometimes with no idea of who these women are or an understanding of what horrible experiences they've had. Why should they trust them without knowing them and knowing they understand and care?[16]" The trials and challenges brought on by homelessness, as well as constant exposure to callousness and disregard by the general population, have caused the aforementioned individuals to mistrust any researcher whom they do not have a genuine relationship. Again, "[a researcher] can't just come into a room full of homeless people they don't know and say, 'here, answer these questions.[7]'"

Interviews with community leaders also revealed a lack of understanding among researchers in regards to the actual plight of homeless individuals. In one instance, a researcher had hoped to ascertain data via the internet, and wanted homeless individuals to take a survey, which would be repeated three times. When the community leader asked the individuals who would be taking the survey who had access to the internet on a daily basis, three out of approximately twenty raised their hand. When asked by the community leader about said internet access, the majority of those who did not have daily access explained that they would have had

[16] "Community Health Leader Interview 2." Personal interview. 19 Feb. 2016.

to take multiple buses to the library and hours out of their day in order to gain access to the internet. This expenditure would have been infeasible for most, and the time spent filling out the survey would have been taken away from the seeking of the bare necessities for survival. The researcher's lack of understanding about the struggles of the homeless led to an infeasible study method and a lack of basic understanding of the homeless individuals he had hoped to perform research on (rather than with).

According to a community leader, in another instance, the United Way, relying on research data that suggested homeless veterans were in the most need financially, decided to eliminate poverty among the homeless in Connecticut, starting with this community. The United Way, although relying on data generated by research, did not have access to the full picture of homelessness as only relationships can provide, and did not understand that starting with families could allow for the prevention of further homelessness symptoms of the children in the families, as early intervention would lessen the time the children spent homeless, thereby lessening time to develop the health effects (both mental and physical) of homelessness. Although starting with veterans allowed for the important and necessary aid of this population, a tradeoff came in that children in homeless families, at an impressionable and formative stage in development, would wait a significant amount of time to gain access to shelter and other necessities, thereby developing more effects from homelessness over this time period in the youth population.[7]

In this section, I provide two examples that demonstrate the differences between two public health research approaches, one in which empathetic relationship creation was not employed, and one in which such understanding and engagement was employed, and how such engagement positively affected study validity. Various public health research programs have been devoted to examining the nutrition in the food supply. Although much of this research has shown that there is a lack of nutritious options available in lower-income neighborhoods, most of them have failed to delve deeper into gaining an understanding of why this might be the case. Researchers gave the recommendation that healthy options be added to the food supply in these neighborhoods, and more should be done to educate these low-income or homeless individuals about healthy eating habits and nutrition. This misguided recommendation was a failure to understand the *population* being served by the bodegas and convenience stores of lower income areas, as well as the struggles of both homeless and recovering formerly homeless individuals. Yes, food stores in lower income neighborhoods have a lack of healthy options, and homeless individuals might have a lower level of knowledge when it comes to eating healthy, but there are reasons behind these deficiencies.

Delving deeper into the story, the community advocate found that the stores cannot afford to stock healthy items, such as fruits and vegetables, as they are more costly than junk food and spoil more quickly. Homeless and formerly homeless individuals, by and large, opt for the least expensive options in regards to food, as survival by any means is a necessity and they cannot afford to splurge for nutritious choices. In turn, bodegas and conveniences stores in such lower income

neighborhoods are not able to sell the more expensive healthy food options, as there is no market for them given the high cost.[7] The research stopped at a recommendation that was not feasible or implementable, given the challenges faced by homeless and formerly homeless individuals. An understanding of the community being served, as gained through trusting relationships and dialogue, led the community leader to understand the reasons behind the lack of access to and lack of healthy food elections by the homeless community as only a deep relational dive can reveal.

Through empathizing with the homeless and formerly homeless individuals - truly understanding their thoughts, feelings, and challenges – the community leader began to understand the actual needs of the community. Although understanding is enough to comprehend needs, empathy goes beyond understanding in actually causing researchers and community leaders to feel what the other party is feeling and react accordingly. In empathizing with the community members, and based on the leader's informal research, steps were taken to address the actual public health problem. The leader advocated for fresh produce and healthy choice government subsidies for stores to carry such choices, and advocated for these subsidy discounts to be passed down to consumers. The community leader, in partnership with government, also developed a plan allowing for the first ten dollars of food stamps to double in value if used on fruits and vegetables at local farmer's markets. In addition, the community being served expressed a desire to learn about healthy cooking, but did not know how to prepare many of the fresh fruits and vegetables being newly offered. Cooking and food preparation demonstrations were organized

at the farmer's markets to enable the community to prepare fresh, nutritious, and newly-affordable meals that would promote health and increase nutritional knowledge. In addressing the root of the fresh food problem, the leader, in partnership with researchers, the community, and government, acted toward addressing the actual unmet need of the homeless and formerly homeless community in a way that was actionable and effective.[7] This effectiveness stemmed from the leader's empathy-based relationships with the community and the mutual trust between leader and population members.

It is clear, from this example, that a lack of empathetic relationships between community members and the homeless and formerly homeless population led to a disconnect and a lack of researcher understanding surrounding the real barriers faced by homeless individuals when it comes to healthy food choices. Yes, access was a problem, but it was not the only, nor the most important, barrier to healthy food choices. Had researchers invested in the time and energy to develop trusting, empathy-based relationships with actual homeless individuals, they would have understood the real needs of the community, allowing such research to have been actionable and effective in fighting the lack of fresh produce and nutritious options available to low income and homeless individuals. As Green et al. explain, "if the health professions and their sponsors want more widespread and consistent evidence-based practice, they will need to find ways to generate more practice-based evidence that explicitly addresses external validity and local

realities.[17] "Applied to empathy's place in public health research, focusing on empathy-based relationships (which entail understanding the research participant as a research partner and appreciating the research participant's stories and experiences) allows for more accurate assessment of local realities to drive external validity and results that are applicable to driving needed changes in public health practice.

*Finding #2: The Importance of **Authentic** Collaboration*

Through the interview process, another red thread that was revealed regarded collaboration and its essentiality to the research process. Collaboration results in actionable research results which are based on real community needs, but it is essential that this research involves *authentic* collaboration. In interviews with both community leaders and formerly homeless individuals, it was revealed that, although the homeless community might be invited to the research discussion as part of CBPR research, this does not necessarily mean that authentic collaboration is occurring. As one community leader explained, "many past experiences with community-based homelessness research had been about checking the boxes to show [the public] you had all these parties.[18]" In other words, the focus of researchers was not on actually getting to know the homeless and their needs, but rather using their presence at a community research meeting to publish results that indicated community input was obtained through CBPR procedures. The homeless

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[17] Green, Lawrence W., Judith M. Ottoson, César García, and Robert A. Hiatt. "Diffusion Theory and Knowledge Dissemination, Utilization, and Integration in Public Health." *Annu. Rev. Public. Health. Annual Review of Public Health* 30.1 (2009): 151-74. Web.

[18] "Community Health Leader Interview 1." Personal interview. 16 Feb. 2016.

individuals involved in some of these negative research experiences "just became an experiment," according to the community leader.

Returning to the community leader's experience with the food supply, the positive influence of authentic collaboration is readily evident. Researchers, in working with community leaders and homeless/formerly homeless individuals, delved deeper into the problem of nutritious food scarcity, investing in the creation of genuine, empathy-driven relationships. Although this research was undertaken by a community agency, it served as a prime example of truly authentic collaboration, revealing the power of bringing multiple parties together to develop empathetic relationships grounded in real experiences. This collaboration and focus on genuine understanding allowed for applicable and actionable results, as they were based on the *lived experiences* of homeless and formerly homeless individuals, rather than a solely theoretically-derived and conceptual understanding of the problem. Although the latter should never be the way research proceeds, based on the interviews with community leaders, some individuals have attempted to carry out research without community input or an understanding of how theory applies to the specific problems of a specific community. Yes, in the example, the problem was a lack of access to fresh and nutritious food, but the root of that problem was the issue of affordability and a lack of knowledge, and this root was only ascertained and understood through an appreciation for the *lived experiences* of the community research partners. Without the trust developed between community research partners, community leaders, and researchers and due to an empathetic appreciation of lived experiences, there would have been no way to create an

actionable plan and result, as the root of the problem would have been neither understood nor addressed. This appreciation within partnerships is based on an "intersecting," and not a "merge." The Community Foundation for Greater New Haven, in developing a guide to empathetic and fruitful community-based research, explains that "Each [person/organization] has their own culture, objectives, and outcomes. There needs to be a clear understanding that they intersect to interact, not to merge, and that they need to embrace the diversity within the partnership.[19]" Empathy is exactly that, an appreciation of diversity. It is an appreciation of another's story, a true valuing of the *lived experience* of another and an acting in accord with and with respect to the individual's story, needs, and desires.

Finding #3: Homelessness Research Must Include a Focus on Larger Systemic Issues

As illustrated by the food system example, public health research must focus on larger systemic issues, and the only way this can be effectively accomplished is to *understand* those issues. The only way to understand these issues accurately is to engage in grappling with and appreciating the *lived experience* of homeless individuals who actually struggle with navigating such a system every day, a concept and technique qualitative public health researchers already employ. As explained by a community leader, public health research into homelessness has largely gone to "peeling off the numbers,[9]" rather than changing a system that does not allow for easy access to resources or even the dissemination of knowledge to the homeless community that resources and help even exist. Research must be *transformational*,

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[19] Ray, Natasha, Wang, Karen, MD. "A Guidebook to Successful Research Partnerships." *The Community Foundation for Greater New Haven.* 5 May 2014. Print.

and understanding the lived experience of homeless individuals through development of empathetic relationships is the only way to gain true insight into the actual research needs of a community.

Researcher-Gained Commentary

The response of the researcher in regards to homelessness research reflects the responses of both the community leaders and homeless community members on a basic level. The researcher asserted that, in order to positively affect health, it is necessary to understand and grapple with the lives of those individuals who will be affected by such research, and in order to do this it is necessary to act with empathy, or an ability "to step into other people's shoes.[20]" In addition, the researcher brought up that the consideration of different perspectives and diving deeper into individuals' stories is essential to empathetic public health research, reflecting themes highlighted by the interviews with community leaders and homeless community members.

In addition to reflections of the other interviews, the researcher brought up that an empathetic public health researcher "does not make assumptions hastily,[11]" a reflection of the previously mentioned appreciation for stories and a delving deeper to truly understand research participants' lives.

Interview Analysis

During the two community leader interviews, a list of the most commonly used words by interviewers was tallied, and a word cloud generated. In anticipation

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[20] "Public Health Researcher Interview." Online interview. 6 Mar. 2016.

of the interviews, I wrote down a list of words I thought might come up, leaving spaces to tally frequencies. Although I had "trust," "relationships," and "respect" on the list, I wound up adding "authentic" before relationships (they were used together a majority of the time) and consider genuine and respect in the same list, given the combined implications of each word. The choice of only analyzing interviews with the community leaders was made in viewing these leaders as the bridge between researchers and homeless individuals. Leaders and their organizations are both facilitating research and interacting daily with homeless individuals with whom they have deep relationships, and so the vocabulary they use to describe the homeless community and research needs is aligned with both research and community goals. Although such a count might not give conclusive analytical evidence as to theme significance, it does provide an understanding of what concepts are most important to community leaders in their daily lived experiences with homeless individuals and communities, as well as what concepts are most on their minds when discussing the area of public health homelessness research.

The words "authentic" and "relationships" appeared far more than other words, as illustrated by their relatively large size in the word cloud. One community member used the word "authentic" fifteen times during the half-hour interview, and the other used it eight times. Relationships was used a total of twenty-seven times when both interviews were aggregated. The words "trust," "genuine," and "needs" also came up frequently, as did the word "actionable." These six words were, by far,

the most frequently heard in interview responses, and it is helpful to examine this in context.

Authentic Relationships

The words authentic relationships are an indication of the need for public health researchers who are concerned with developing relationships based on a mutual understanding and appreciation, rather than a one-sided "collector – provider" relationship based on data collection and a disregard for the source of said data, an individual with a story to be appreciated. Authentic relationships transform the nature of public health research into a true partnership dedicated to both building understanding and truly improving a community's health.

It is necessary to step back and examine the word "relationship." Insight gained by speaking with a public health researcher at Yale with over twenty years of experience shed light on the dual meaning of the word "relationship" in research, as did a literature examination. Often, "relationship" is used as a code word for access, in the sense that developing "relationships" with community leaders will enable the researcher to gain access to a population whom they can research. In this sense of the word, such individuals are akin to cultural brokers, and no true empathy occurs, in that the researcher and the broker/community members are not looking to gain trust and a deeper knowledge of each other; rather, it is a gaining of access to research subjects without the development of meaningful (and insightful) relationships that both promote human dignity and allow for study validity. In my study, "relationship" refers to the development of such a bond, not simply a contact through whom a researcher can gain access to data or a study pool.

Trust

The word trust stems from the creation of authentic relationships. Both on a practical and ethical level, trust is essential to public health homelessness research. On a practical level, trust allows research participants to answer questions freely and honestly, as they are confident the researcher will not betray them in any way. On a deeper, more ethically-grounded level, trust is an essential part of public health research dedicated to the greater good, aimed at bettering humanity through rightly-ordered and equitable social interactions. Trust validates the stories of both researcher and participant, in that a mutual sharing allows for the moving toward a common goal of better health for all through knowledge and the sharing of such information.

Genuine (Respect)

The concept of being genuine is essentially respect, actualized in relationships. Genuine interaction entails an authentic, actual appreciation for the research participant and his or her struggles, triumphs, and needs. Genuine interaction calls for participants not to be viewed as a means to an end (publishable results), but rather, an integral part of the research process and partners in the bettering of public health.

Needs

The word "needs," in context, referred to the needs of the community, the actual, real needs of the homeless study participants. Researchers should aim

toward improving the health of communities through an understanding and appreciation of such needs, as explained in the APHA guidelines. The only way to understand such needs is through the creation of authentic, genuine relationships based on trust between researcher and community member, as this allows for the free flow of honest information in both directions. Such community feedback is essential to addressing the actual needs of the community through research targeting such needs.

Recommendations and The Way Forward

Through an examination of the public health issue of homelessness, it is evident that empathy does indeed play an essential role in actionable public health research. Although this might seem like a given, the evidence presented by community leaders of research undertaken without an empathetic approach and the

positive difference in impact when compared to research that was undertaken with an empathetic approach makes it necessary to reassert such an essential fact. Employing empathy in the research process is both a practical and an ethical imperative. Practically, empathetic research allows investigators to understand the true needs of a community, also enabling them to give investigators honest and reliable information that will result in objective results. Ethically, empathy in public health research acknowledges community members' humanities and stories, allowing them to fully participate in an equitable partnership with researchers.

Researcher Self-Assessment

Given the demonstrated necessity for empathy and true respect for community members in public health research, a recommendation comes in the form of researcher self-assessment prior to any community-driven project. After analyzing the literature and my interview findings, five reflection questions have been developed as a tool for researchers to self-assess their own approach and ability to employ empathy in a project, prior to project commencement. This "Researcher-Community Member Sensitivity and Knowledge Assessment" will serve as a proactive tool to guide researchers in empathetic, equitable, and empowering research practice[21, 22, 23, 24].

1) What knowledge of the community being researched do you have on a personal level, and is this knowledge relationship-driven?

[21] Ray, Natasha, Wang, Karen, MD. "A Guidebook to Successful Research Partnerships." *The Community Foundation for Greater New Haven.* 5 May 2014. Print.

[22] "Community Health Leader Interview 1." Personal interview. 16 Feb. 2016.

[23] "Community Health Leader Interview 2." Personal interview. 19 Feb. 2016.

[24] Green, Lawrence W., Judith M. Ottoson, César García, and Robert A. Hiatt. "Diffusion Theory and Knowledge Dissemination, Utilization, and Integration in Public Health." *Annu. Rev. Public. Health. Annual Review of Public Health* 30.1 (2009): 151-74. Web.

2)   What will be done to ensure each community research participant is treated with respect and equality in informing the research process?

3)   What will be done to develop authentic relationships with community members participating in the study, as well as with community members to which the study has import?

4)   How will trust be developed between researcher and community members to ensure both honest participation and a mutual appreciation for stories (a "working with," rather than a "working for/on")?

5)   If significant results are found, how will these results be acted upon and disseminated to community members in an easy-to-understand and actionable format?

The above self-assessment would allow researchers to assess their capability to empathize with the community members their study pertains to, and will serve as a guidepost to the development of a post-research plan to both act upon and disseminate findings. It is a proactive approach to ensure research serves as an empowerment tool for community members through an appreciation of individuals and their stories.

Conclusion

Although public health is, by definition, a population-based science, it *is* personal, in the sense that many studies rely on community member and participation and input. In addition, public health provides prescriptions for diagnoses of health-affecting conditions that affect individuals. Every junction between researcher and participant is an opportunity for trust-building and empathetic interaction. In fact, such opportunities present a mandatory instance of empathetic interaction, both in accord with the ethical guidelines set forth by the APHA and a respect for persons and human dignity, essential to performing research both in line with true public health impact through the improvement of

population health. As asserted, without a true understanding of a community and the public health item being researched, the validity of results is jeopardized, as illustrated in the examples provided through my interviews with community leaders. Public health researcher David Buchanan explains that it is necessary to appreciate and respect human autonomy and a researcher's moral responsibility to understand such autonomy, including decisions and wishes of research participants.[25] This builds on his earlier call for the focus on human dignity in research relationships by respecting the "other." The assertion of this paper is that such appreciation can only come from truly understanding participants' stories, which will foster a valuing of participant input and expertise. Effective and ethical public health research can only take place through a deeper understanding of stories and the real issues community members face, and this is only possible through truly empathetic public health practice. Research based in lived experiences must be further encouraged, given the positive results presented in this paper. Empathy-driven qualitative and ethnographic research, both focused on understanding and relating to lived experience and the development of meaningful relationships, are a way forward in this regard, as is a further appreciation for individuals' stories as part of a community's story collection, essential to both the validity of research results and a championing of human dignity.

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[25] Buchanan, DR. "Promoting Dignity: The Ethical Dimension of Health." *International Quarterly of Community Health Education* 36.2 (2016): 99-104. Jan. 2016. Web.