DRAFT:

*Chapter to appear in Taos Institute's, Harnessing Humanness in Healthcare - Appreciative and Relational Practices, 2020*

# Creating an Ensemble for Performing Health

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**Abstract**

"Creating an Ensemble for Performing Health," introduces a relational practice of health and healing--the "Health Team"--that is social, collaborative and performance based. The Health Team model is a self-organized grouping of the patient, friends, family and professionals that as a unit navigates the complex, often contradictory, sources of information, recommendations and experiences of illness in 21st century America. It is a challenge to the individual bias of current health practices. The Health Team, organized in response to complex medical issues such as cancer or heart disease, meets regularly and, under the direction of the patient, takes ownership of every aspect of the illness that includes pain, disability, emotionality and medical decision-making. The chapter presents the model, provides examples of the practice, samples of dialogue, and an analysis of what has been learned over 30 years of using health teams in the service of creating a new performance of health.

Key Words

Ensemble, Performance, Health, Teams, Cancer

The chapter introduces a practice of health and healing known as "The Health Team," that the authors, Susan Massad, a retired primary care physician, and Barbara Silverman, a practicing clinical social worker, presented at the Taos Institute conference on Relational Practices in Health and Healthcare in November 2016. The practice has its roots in the consumer-driven health movements of the 1960s and 1970s, is located within the Social Constructionist movement, and is one of several relational health practices--patient-centered care, collaborative care, and socio-cultural-biological--that is challenging the individual bias of current health practices.

The Health Team concept has evolved out of a diverse community of social activists that have been exploring relational practices in education, psychology, mental health, and health for over 40 years. The teams described in the paper operate within this larger community that includes the East Side Institute and affiliated Social Therapy practices throughout the country. Up to this point in time most participants in the Health Teams have participated in the larger community and have had extensive experience working in groups of all kinds. Both authors have been directly involved with, or consulted with, the Health Teams that are described in the paper.

We are eager now to present the Health Team approach to a broader audience as we feel the practice has the potential for helping many others who are grappling with complex and/or chronic medical issues that are part of living in 21st century America. In the chapter we will describe the workings of a few of the Health Teams, present examples of conversational dialogues from some of the teams and share what we have learned to be

the benefits and challenges of this collaborative process.

## Why a Health Team?

The practice of creating a social unit for health care evolved out of our experiences as clinicians.

### Massad

Five years ago I retired from the practice of medicine where I had been a physician educator for over 50 years. I was trained in a model of illness, the "medical model," that locates disease and all its manifestations firmly within the individual. Never fully embracing this approach I found the separation of the individual and his/her illness from their activity in their world/society/community both arbitrary and inaccurate. In the late 60's I joined the faculty of the University of California at San Francisco at a time when medicine was undergoing profound changes in payment systems, patient access to health care, and many were challenging, both inside and outside of the academy, the gender, race, class and cultural biases of health care. It was here that I began my nearly forty-year journey to discover an alternative approach to health and healing that brought, in the broadest sense, patient and his/her community together.

In the early 1980's (twenty five years into a successful medical career), I met Dr. Fred Newman and Dr. Lois Holzman, the founders of the East Side Institute (ESI). I was introduced to Social Therapy, a philosophical, performatory, postmodern approach to helping people to grow and develop, emotionally, socially and intellectually, by relating to them as social performers, builders and creators of their emotional and physical lives (Holzman, 2017, Holzman & Mendez, 2003, Newman, 1996). Social Therapy, a group

approach, was challenging the assumption that our subjective responses to life issues (pain, despair sadness etc.) were individual and private, as well as its corollary assumption that treatment or help is the responsibility of the person in which those responses reside. In the chapter "Whose Pain is it Anyway" of *Let's Develop* (1994) Newman points out that "social therapy teaches people to give up 'private ownership' of their pain by giving their pain to the group…What we have found is that socializing pain changes people's experience of it" (pp.87-88).

The socialization of illness, that is, giving up one's private individual ownership of it, is not an easy task. To me, this is where development comes in. In *Lev Vygotsky Revolutionary Scientist* (2013) Newman and Holzman point out that development is something human beings do together rather than evolving "naturally" from within. It is our relationality that allows babies to develop into toddlers and toddlers into speakers. Performing is how human beings develop. It is by being supported to perform "other" than who we are that we develop emotionally-socially- culturally-intellectually. This process of transforming the existing conditions into something qualitatively new applies equally to our pain, our disability, our migraine headaches, our victimhood. When we create an ensemble and try out performances of our societally over determined emotionally and identity-based social roles we are creating who we are becoming, and we are doing things we don't know how to do, in the way that babies do.

As a medical practitioner I found Newman and Holzman's discoveries about performance and development transformative of my practice. I began to experiment with group medical visits, creating collective learning environments in the form of community

workshops on HIV, cancer and hypertension, and organizing advocacy groups within the community (Massad, East Side Institute vimeos.com/channels/256189).

The Health Teams are a product of 35 years of work with Newman and Holzman and colleagues from the East Side Institute to bring the discoveries of Social Therapeutics, performance, development and building the group/ensemble, to my practice of health and healing (Massad, 2003).

**Silverman**

I have been a psychotherapist for over four decades. As a social therapist and faculty member of the East Side Institute, I practice, consult, train, mentor and supervise clients both here in the US and internationally. The scope of my work includes eating disorders, youth groups, group therapy with adults, community organizing and work on health issues.

As a young woman I worked in a variety of mental health settings that included a day treatment program with adults, a locked psychiatric unit for children and adolescents and, later, a youth storefront in a community mental health center and an adolescent medical clinic. These were all experiences that motivated me to pursue a master's degree in social work where I was looking to combine my interests in theatre, working with young people, health and therapeutics. My goal was to create contexts that supported adult/youth partnerships where young people could be taken seriously and take responsibility for living their lives (Feldman & Silverman, 2004, Holzman, 1997).

In social work school I found the dualisms of psychology that separated the patient's emotional life from their physical life, their relational life and their community life to be deeply problematic in that the practice viewed emotions and emotional

problems as being located primarily in the individual. At a crossroads in my career, searching for a therapeutic approach that could empower both providers and clients, I met the East Side Institute and began working with Drs. Fred Newman, Lois Holzman, Susan Massad, and others (Holzman & Mendez, 2003).

When I met the East Side Institute, I was using performance as a tool for expression in my mental health work with youth. I found Newman and Holzman's understanding of social performance and development to be transformative of my therapeutic work. It continues to be a revelation to youth and adults in my therapy practice that we can develop our capacity to make performance choices at any moment in any situation. Learning to ask the " how do we want to perform our pain, rage, disappointment, frustration with others" is the engine to our emotional and social development. It has given me the tools to challenge people's belief that "this is who I am" and their belief that new things cannot be tried without first knowing how to do them.

Working with the ESI has changed my life and revolutionized how I practice therapy. It has given me the opportunity over the last 35 years to advance and lead the process of collectivizing and socializing our emotional/physical lives in social therapy groups all over the world.

## What Is a Health Team?

The Health Team is a self-organized grouping of friends, family and professionals who come together at the request of the patient to collectively impact on the experience of illness. Participation in the team is voluntary, meeting times flexible and based on the needs of the team. There is no template. The team sets up structures for journaling,

attending physician visits, assignment of research and information processing and reporting of symptoms. Most of the Health Teams so far have been organized in consultation with one of us to respond to the needs/demands of a complicated and/or serious illness. The first Health Team was initiated in the mid 80's and since that time we have had experience with approximately 30 health teams that have met anywhere from one month to three years.

While the Health Team addresses what are considered traditional illness-related concerns – such as, pain management, sleep difficulties, side effects of medicine, problems with diet – the team also responds to the subjective and emotional experiences of everyone on the team. The over-arching task of the team is to continuously be engaging the question: How are we going to create the most developmental life possible, that includes, but is not dominated by, the constraints and needs of a particular illness?

We have found that central to the success of the Health Team experience is the patient inviting the team into the process. The socialization of the illness is supported through conversation, journaling and the direct participation of team members in the process of care. In meetings the team share information, their experiences and reactions as they collectively make decisions as to how the illness is to be performed in day-to-day life.

The transformation of the illness activity from an individual private activity to a social performatory relational activity has been one the most contentious elements of the work of the Health Team. The individual bias of the traditional medical model of health runs deep and the collectivization of the illness, i.e., the evolution of *my* illness to *ours*, is not an easy task. We will be presenting some of these struggles over ownership in the

case presentations.

The Health Teams can be seen as part of the broad effort to amplify the patient's voice. Support groups provide informational and emotional support to patients and families. Consumer driven, disease specific, self-help organizations provide a wealth of information about treatment options, self-care, and personal experience with various treatment approaches. These efforts provide invaluable service to patients and families as they struggle with the impact of serious illness on their lives (Till, 2003). To us, what differentiates the Health Teams from these other efforts is the focus on creating a new formation for health and healing that socializes and collaborates on the entirety of the illness activity. Although the material the team works with are the varied needs and demands of the illness, the question of how we are going to do this activity together leads the dialogue. We have found that this collective activity opens up the possibility for the growth of everyone involved in the process.

## A New Performance of Health

The first experience with a Health Team, before we had any sense of what it was or could be, was with PG, a 58-year old female college professor and community activist who had developed a recurrence of breast cancer that had metastasized to the skin and bones five years from the initial diagnosis and treatment. At that time in the life of cancer, the recurrence was considered treatable but incurable. In her Social Therapy group PG expressed a desire to create something new and positive with this end stage of her life.

In most of her life PG had been an avowed loner, and the group's direction that she work with a team of friends to help her with the task of creating a different life was a

stretch. With reservations PG agreed to share her process with others and a Health Team composed of Massad, a social therapist from PG's group and two close friends came together to work with her to live the most developmental possible life with her cancer (Newman, 2010.). Without knowing how or what they were doing, PG and her team set off on a three-year odyssey discovering the "how and what" as they went along.

The team decided that in order for them to be co-owners of the illness and make it theirs, PG needed to share her experiences. She kept a daily journal of her symptoms and feelings and reading from the journal became a part of every team meeting. From her detailed notes the team learned that pain from the bone metastasis was the most disabling aspect of PG's illness and discovered that PG's pain was most severe when she was alone. It was in this space that she was most prone to experiencing self-pity and victimization that took the form of thinking, "Why me? Why was it my cancer that reoccurred at the magic five year mark when most others with this disease were declared cured?" In response to this information the team made the radical decision that PG should never be alone with her pain and helped to organize a support group from PG's community of friends. Team members and friends spent the night and weekends with her, planned and operationalized a schedule of daily visits and accompanied PG to doctor visits and social engagements. The "never-alone-plan" worked. PG did not experience severe pain or require narcotics level pain medications for the remaining three years of her illness. Although at times PG took back private ownership of the pain and other symptoms, in most cases PG's struggles to share her symptoms became the work of the team. In the years before PG's death all decisions about her care and management were

made collectively with the team. PG was a contributing member to her Social Therapy group and to her community. She died at home with friends and family by her side.

A few of the discoveries we made during this three-year journey with PG and metastatic breast cancer: The team was able to improvise and work more creatively with aspects of the illness (such as pain, nausea, cynicism and fear) than PG could do on her own; as a collective the team was able to make and support more daring medical and therapeutic decisions; as a group we were able to mobilize a wide range of relational resources. Through conversations the team was able to break through the dualisms of medical practice, making no separation between the emotional/subjective issues of illness and the more physical aspects of illness. Most importantly, the team learned that the collectivization of illness, moving from "mine" to "ours," was a dynamic, ongoing struggle throughout the life of the illness.

ES is a 70-year old self-employed woman who has lived for many years with multiple chronic health issues — irritable bowel syndrome, (IBS), chronic fatigue, allergies, high blood pressure, migraines and fungal infections. In spite of her illnesses she has been able to build a successful medical billing service, as well as provide invaluable volunteer support for a number of community based projects. Several years ago, when her chronic bowel symptoms worsened, friends suggested she work with a health team to help her manage the multiple and complex treatments recommended by her different physicians.

In speaking to ES about the Health Team experience she said she had been fearful of turning over decisions to others. She did not want to lose control of things and thought the process of sharing her illness would be disempowering. She was also afraid that

people would be judgmental and moralistic with her. With, or in spite of, her reservations she invited four close friends to be on her health team. The major issues the team has worked on are: How to help ES to manage the sometimes disabling symptoms of pain and distress from the IBS; and how to create a more directive performance with her multiple physicians.

For many years prior to having a health team, ES would respond to the "how are you doing question" by presenting a lengthy dissertation on all her ailments that included how poorly she had been treated by the medical establishment. Friends and others she consulted about her medical issues found these negative and seemingly endless accountings debilitating and impenetrable. The Health Team realized that the way ES talked about her illness made it difficult for her to get help and began to work with her on how she presented her health issues, i.e., how she was performing her health. During the course of this work ES would become angry as she felt people were being moralistic and judgmental and at various times wanted to fire some of her team members or abandon the entire endeavor.

The team has worked collectively to challenge ES's individual ownership of her story and at one point decided to start each Health Team meeting with a song by ES, who is a beautiful country western singer. Team members say this small change has helped to create a more positive environment for the health conversations to take place. In one of our interviews we asked ES if she disagreed with the team's assessment that the way she talked about her health issues had a negative impact on the work of the team and, in the long run, on her health. ES feels she has been won over to the team's position while she continues to struggle with her new more positive performance. Although many of ES's

symptoms are still present the team reports that there is more playfulness and fun in their meetings and they feel freed up to explore more varied treatment options and fulfilling life activities.

DC, a 59-year old African-American male, is the city leader of a large non-profit organization that he helped to build from the bottom up. Several years before his health team was formed he had been diagnosed with Congestive Heart Failure secondary to severe Coronary Artery Disease and had undergone successful coronary bypass surgery. Two years later he again experienced symptoms of Congestive Heart Failure. He was hospitalized as an emergency and it was discovered that his cardiac function was severely impaired. Following a stent procedure to unblock the coronary arteries, Massad advised DC to convene a Health Team to work with him as he underwent the slow, painstaking process of cardiac recovery. A Health Team was organized and began working with him on what was needed for his survival, as well as what he needed in order to continue to play a leadership role in the non-profit organization that was a driving force in his pre-illness life. His team was involved in all details and decisions about DC's life activities, from daily schedules and cooking facilities to cardiac rehabilitation schedules and socializing.

From the beginning a major theme of DC's Health Team work has been to help him reorganize his non-profit work. DC grew up in a poor family with a very strong work ethic. Prior to his own illness he viewed those who withdraw from work because of illness judgmentally. "They were slackers!" DC applied these same standards to his own work. He felt he was responsible for every detail of the program.

Three months post the episode of severe CHF and stent placement, while DC was still wearing a defibrillator vest and on a very restricted work schedule, he announced to the team that he was traveling to NYC for a three-day work meeting. The team was shocked that DC would consider travel at this point and expressed concern that he had made this decision without the team's input. Team member HP suggested that DC talk about the plan with his team and he agreed to hear what the team had to say. DC said he had not been thinking that the trip was a Health Team issue. For him it was a work decision. Members of the team spoke to what a trip from Chicago to NYC entailed and discovered that DC was vastly underestimating the emotional and physical stress of such a journey. Based on the team discussion DC decided to cancel the trip.

The trip to New York was the first of many struggles with DC around his almost driven need to oversee everything in the youth program. In a recent interview, DC told us:

> *I felt good about the team intervening on things that I thought were directly related to my health, like diet, exercise, doctor's appointments. I was less open to them assuming responsibility for my work life. I do not like missing work stuff and was resistant to following the direction of the Team particularly when they gave me push back on my hours of work or raised with me their concerns about traveling to NYC for organizational events. When disagreements with my Team about work came up I felt they did not understand how important my work is. I am responsible for what happens in Chicago. I am the bottom line. The team meant well but they just didn't understand how important things are.*

We asked DC how these disagreements with his Team got resolved.

*What helped is that the Team took what I said very seriously. In the language of improv they "Yes/And-ed" my concerns and worked closely with me to reorganize my work. In the early days of my recovery they helped me to set up things so that my staff would check in with me remotely when they were producing big events so I felt included and less concerned about not being actually present. For me, what was key was that the Team showed me they understood how important the work was to me. It also helped to have other seasoned community organizers on my team who understood some of my concerns about abandoning the work.*

DC's health and cardiac function have improved remarkably over the past year and the team continues to operate with a conference call every two to three weeks. In speaking to DC about how the illness and team experience has impacted on his feelings about work, he said,

*I had not thought about this but I realize that going back to the way things were does not include my work team's development. I am thinking now that I can use their growth to free me up to do more outreach and expand our organization. Also that I do not have to go back to 10-hour days where I had to be everywhere and do everything myself.*

## Impact of the Health Team

We learned from interviews with Health Team participants that the process was most impactful in three areas.

### Changing the Relationship of Patient to Their Disease

As people became more comfortable and accepting of the process, their experience of illness changed. DA (who has been both a patient and member of Health

Teams) told us, “I have learned from various health team experiences that the most important thing is being able to give to other people. To not just focus on me as the person with the illness but on my relationships with others.” DC told us, “I was always the caregiver in my family but the team helped me to let others help and support me.” BT said, “I learned that I could be more playful and curious about my health issues. When I develop a new symptom I am now more curious and do not feel that I have to accept old definitions, such as a new pain is a bad sign.”

**Positively Impacting On How Health Team Members Perform Their Health**

Uniformly, participants in the Health Teams said the experience had a positive impact on how they perform their own health. SF (a Health Team member for three years) said, “We have formed a health team in my household that supports us to work with our doctors in new ways. It helps us to prepare questions when we go for a visit. It helps me to do my health as an ongoing activity, not as just a one-time effort.” HP said, “I am more inclined to talk about my health issues with my partner and we work as a team.” Team member JH said, “I am more grounded in my own health issues. They are not so dramatic and I am less victimized by my health problems.” MW discovered that being on a health team opened up new ways of doing health. He told us, “Guys don’t like to ask for help.”

**Transforming The Relationship Between Patient And Provider**

We found that as the teams begin to work as an ensemble and participate in the totality of the patient’s health activity, the interface between patient and provider became a prominent part of the conversations. The following are some comments from Health Team members about how their relationship with providers has changed in this process.

HP said, “I work with my doctors differently. I feel more open to asking them questions and preparing questions in advance.” LC’s reactions to her providers and the dysfunctional aspects of the health care system were often volatile and anxiety producing. In assessing the health team experience LC said, “ It was of tremendous benefit to me in helping me to work with my doctors. It gave me permission to say no to them. It helped me to be more worldly with my doctors and my relationship with my primary doctor has been transformed in a positive direction.” A number of health team participants told us that the experience helped them to talk about their health issues differently, to be more direct, less anxious and to express what they wanted from the provider.

**Challenges and Benefits of the Health Team**

The Health Team is both a provocation and a challenge to the medical model that determines how most of us, patients and providers, approach the medical encounter. We have found that participation in the Health Team process can have long-term benefits for all those who participate. In this next section we will present some of the key benefits and challenges of the Health Team process.

As can be seen in our examples, a major challenge to creating a new performance of health is the difficulty people have is in the transformation of their health activity from *mine* to *ours.* To fully accept that activities such as decision-making, one’s subjective and emotional experiences or work related issues that impact on health are no longer private or individual is difficult. People in great pain continue to insist, at times, that the pain is theirs to experience individually and to remedy through their own means. The conflicts and struggles over ownership is prime material that the Health Teams work with. In many case we have found that these struggles can be a catalyst for growth. (Holzman, 2017)

One of the major benefits that collective ownership brings to the medical encounter is in decision-making. As the team assumes responsibility for the illness activity the individual and family are relieved of the stress of making sense out of the vast array of information and therapeutic choices presented to them on their own. "Let the patient choose" is a mantra heard today from both traditional and alternative medicine but this advice is most often given without direction as to how to go about the choosing activity. Many teams over the course of their existence turned into mini research institutes as they pondered evidence-based practices, read the newest reports and consulted experts. Thus armed, the teams are in a position to incorporate the wisdom of medical science into a decision-making process that also includes the patients' needs, values, wants and resources.

In contemporary health care the relationship between patient and providers and their institutions of care is often fraught with difficulties. Frustration over systemic issues such as appointment scheduling, information retrieval, leaving and responding to messages, or the frequent complaint that "my doctor was in a hurry and did not seem to be listening to me" are recurring themes when people speak about their experiences with the medical system. In our opinion these issues are barriers to patients accessing the medical help they need and severely limit the possibilities for collaborative activity between patient and providers.

The shared strengths of the Health Team have produced more effective strategies for navigating the often-difficult health care system. For example teams participated in developing questions in advance of the doctor's appointment; they created a buddy system for medical visits; and the regular meetings served as a place to process

information and recommendations that are received from practitioners. Through their conversations people learned that they could question the authority of the medical establishment and came to value their conflicts and emotional responses to illness (Garrison, 2007, Sontag, 1979).

Throughout the course and life of a complex and/or chronic health issue, many patients visit multiple specialists who then recommend tests, procedures and changes in the treatment regimen. When functioning well, the Health Team takes responsibility for evaluating these recommendations. They look at both the content (the *what*) of the recommendation and also ask *how* questions, such as how to evaluate the recommendation, how/when to request more information, how to make the best decision, how are we going to do this illness together? It is in responding to *how* questions that the team most often comes into conflict with medical authority. Stepping out of the medical model can be a scary and emotional experience for all involved. We have learned that in making unconventional decisions it is important to have buy-in from the entire team as they take full responsibility for *our* decision.

The Health Teams are not unconcerned about *what* questions, the knowledge questions that are more often answered by professionals. However, the team's expertise is focused on *how* we are performing our health activity. Serious illness is rarely resolved or managed with one diagnosis, one decision or one plan. The *how* questions (such as how are we going to proceed given the diagnosis, the recommendations, the symptoms) can be the most useful when responding to the ongoing, ever changing course of a chronic illness.

Several of the teams worked with people who died in the course of the illness. Many participants found that the process of sharing or collectivizing end-of-life activities transformed all of our relationships to death. Death became less fearsome, more approachable and something we could respond to in new ways. Although loss was part of this experience, many participants also gained a deeper appreciation for life and death as a continuum (Berman, 2014).

## Conclusion

Illness is one of life's serious events that affects just about everyone. How we perform it has an enormous impact on the health of the individual and the society at large. The health team model has been developed at a time when medical science has more to contribute to healing than ever before. Patients and family have almost unlimited access to medical information via the internet, popular press, patient advocacy groups and personal narratives. And medical practice is a source of near continuous complaints and unhappiness from people across political, social and economic spectrums. The Health Team model is our contribution to a practice that can positively grow the patient's sphere of resources as part of the complicated and ongoing process of creating health and wellness in 21st century America. In so doing, it is our hope that the best that medicine has to offer can be used in support, not only of better health outcomes, but of lives more developmentally lived.

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