



The National Society for Social Work in Health Care

# Advocacy in Health Care Social Work Practice

William J. Spitzer, PhD / DCSW  
Editor

*The Select Practice Series:*

*ADVOCACY IN HEALTH CARE  
SOCIAL WORK*

Prepared by:

The National Society for Social Work Leadership in Health Care (via)  
Fernley and Fernley, Inc.  
Philadelphia, Pennsylvania 19103-1443

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# *ADVOCACY IN HEALTH CARE SOCIAL WORK PRACTICE*

## ***The Exemplars in Practice Series***

National Society for Social Work Leadership in Health Care

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## Preface

This volume, the twelfth in the *Exemplars in Practice Series*, focuses on one of the most fundamental of all health care social work skills – advocacy. Eleven contributing authors put forward the principles and practice of advocacy, highlighting significant impacts that social work has had on patients, families, health care provider systems and communities at large.

Social work has characteristically focused on championing human rights, the welfare of the needy and the promotion of self-determination through empowerment of individuals and communities. Within the health care arena, an unending array of issues and circumstances arise that speak to the need for social work advocacy. For a significant percentage of the population impaired health conditions are affected by a myriad of social determinants and unequal access to health care services. This occurs in an otherwise wealthy nation with the most sophisticated health technology and resources available.

It is in this context that our contributing authors make note of efforts to address systemic issues of public health and health care delivery. Their work mirrors the original efforts of legends like Ida M. Cannon and Dorothea Dix, striving to draw public attention to injustices and public needs, promoting the collaborative use of resources and then exercising competent leadership in the evolution of creative new community health programs.

Passage of the *Patient Protection and Affordable Care Act of 2010* was prompted by increasing concern for public health and the realization that more effective and economical ways could be found to meet the basic needs of Americans. Inherent in the Act is the focus on integration of all in- and outpatient service delivery contexts as well as the enhanced cooperative utilization of health care practitioners. This dramatic piece of legislation, the most significant since Social Security and Medicare/Medicaid, provides the backdrop for many of the initiatives revealed in this text. Readers will find the creativity, perseverance and competency of these efforts to be energizing. They may serve as models for replication and/or inspire thoughts for yet other service developments.

The future holds promise for expanded involvement of social work practice in health care. It is the responsibility of professional practitioners to recognize opportunities in which to apply our knowledge, skills and abilities while advocating on behalf of the needy. This text hopefully serves as a catalyst to that end.

Dr. William J. Spitzer, DCSW  
National Society Editor

## EDITOR'S NOTE

The Editor wishes to express his gratitude to the National Society Publications Committee whose time and support contributed much to the production of this text. Committee members include Judith Trachtenberg, Kay Davidson, Adrienne Farrar, Patti O'Donnell, Carlean Gilbert, Katherine Perone, Pam Thompson and Linda Brandeis.

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# ***Advocacy in Health Care Social Work Practice***

## **OVERALL DESCRIPTION:**

This text focuses on the advocacy function of health care social work practice. It defines the concept, its evolution and significance. Six major examples are provided which reflect advocacy in action. These examples demonstrate social work leadership in identifying patient care issues, collaborative program planning and implementation of services designed to not only address care needs of patients and families, but enhance service delivery efficiency and effectiveness. Attention is given to the skills and techniques requisite for introducing change into health care systems dealing with increasingly complex patient care needs and operating in fiscally-driven environments.

## **LEARNING OBJECTIVES:**

Upon completion of this publication, readers will be able to:

1. Understand the concept of patient advocacy, its historical evolution and central role in health care social work practice.
2. Recognize the unique challenges experienced by nephrology patients and the advocacy that led to reformulating social work practice to meet both changing patient care needs and provider system operational concerns.
3. Describe the functional operation of a health home program and the advocacy efforts associated with its implementation in a major urban health care system.
4. Understand the collaborative process by which change was introduced leading to a fundamental redesign of health care services for an oncology patient/family population.
5. Describe the constructive impacts on both patients and provider system from advocating for change in service delivery to “super-utilizers” of emergency department services.
6. Recognize the impacts of PTSD and TBI on military service personnel, their sexual health and intimacy needs and the advocacy leading to creation of a specialized care program with implications for national expansion across the military.
7. Describe the evolution of a health system based respite program that provided needed shelter and health care to an urban homeless population while contributing to declines in inappropriate use of emergency department services and rehospitalization.

# ADVOCACY: THE BASIS OF SOCIAL WORK PRACTICE

*William J. Spitzer, PhD/DCSW and Kay Davidson, DSW, MS*

## INTRODUCTION

Advocacy is a fundamental underpinning of social work. Advocacy is such an elemental component of practice that over the years it has been repeatedly viewed as literally synonymous with social work (*Addams, 1912; Nees, 1936; Spano, 1982; Kahn, 1991*). As Litzelfelner and Petr (1997) suggest, “the social work profession considers client advocacy an ethical responsibility and a primary function of social work practice’ (p. 393). In this vein, in March 2015 at Social Work Day on the Hill, former congressman and social worker Ron Dellums (D-California) said that social workers, more than any other professionals, are best trained to work with lawmakers to tackle pressing societal ills such as poverty and ensuring equal rights for all.

The central place of advocacy in social work practice makes it in many senses a unifying aspect of the profession. Clinically oriented workers advocate for clients to receive social services and gain access to other resources and they encourage clients to become their own advocates. In like fashion, macro oriented social workers advocate for policies to be adequately implemented or changed to meet client needs and they assist clients and communities in representing and advocating for their own programmatic resource needs.

Schneider and Lester (2001) suggest that the roots of advocacy can be traced to the profession’s ideal of helping individuals, groups and populations who are unable to help themselves. Gilbert and Specht (1976) similarly regarded advocacy as a response of social work that supports the pursuit of social justice. This perspective is professionally formalized in the Preamble of the National Association of Social Workers Code of Ethics (2008) which states that social workers strive to end forms of social injustice by engaging in various practices that include advocacy and social and political action. The Code goes further and denotes advocacy as a function for social work administrators (*Section 3.07a*) and practitioners (*Sections 3.07b, 6.01 and 6.04*) as they act to have a positive impact on the welfare (including resources) of their clients.

## HOW DO WE DEFINE ADVOCACY?

Predictably over the years there have been a myriad of definitions for the term “advocacy”. These have made reference to assisting patients in overcoming adversities, influencing change and promoting self-fulfillment. The Social Work Dictionary (*Barker, 2003*) defines advocacy as: “1) the act of directly representing or defending others; 2) in championing the rights of individuals or communities through direct intervention or through *empowerment*”. It points out that advocacy is a basic obligation of the profession according to the *NASW Code of Ethics*. In this regard, Schneider and Lester (2001) have defined social work advocacy as:

“...the exclusive and mutual representation of a client(s) or a cause in a forum, attempting to systematically influence decision making in an unjust or unresponsive system(s)” (p. 65).

This conceptualization of the term notes that the collaborative relationship between an advocate and a client is unique, with shared, reciprocal, interdependent roles. The advocate is active in the work, using all available media to communicate on behalf of the client and his/her cause. Use of the word “systematic” conveys a sense that an advocate applies knowledge and skills in a planned, orderly way, giving thoughtful consideration rather than acting on intuition. The ultimate goal of advocacy is to influence decisions to such a degree that they are altered or changed for the benefit of client or community, at least in part as a result of the advocate’s intervention.

## **HISTORY OF ADVOCACY IN THE PROFESSION**

As Charitable Organization Societies developed at the turn of the 20<sup>th</sup> century, advocacy was central to interventions to combat the abuse, neglect, exploitation and oppression experienced by minority and ethnic populations within some social systems. The notion of advocating and advocacy is thought to have first appeared in *The Proceedings of The National Conference of Charities and Corrections* (Sanborn, 1897; Smith 1897) and to have suggested that social work has a responsibility in the legislative process. The advocacy effort is intended to ensure that legislation for the public good is effective and enforceable. Advocacy involves exerting influence and developing collective action to promote change (Johnson, 1923). The progressive era (1890s-1920s) was marked by efforts to have an effect on fundamental social concerns ranging from labor force exploitation, unsafe workplaces and disregard for child welfare to the abuse and oppression of immigrant populations. The term advocate was used widely during the progressive era. Regulatory achievements of the period resulted from progressive actions and Jansson (1993) notes that Progressives served as precursors to the development of the modern welfare state by championing the role of government in addressing a range of social problems (p. 143). In all these areas, as the social work profession was developing, social workers became advocates both for services to clients and for social policy changes.

Although social work had a long tradition of taking action on behalf of clients, the concept of advocacy did not become integral to practice with clients until the 1960s. It entered the profession with implications for social workers protecting rights of clients and finding themselves in adversarial positions within their agencies. As McGowan (1987) notes, the advocacy functions of direct service workers were seen as a way to reduce tensions between supporters of individual treatment and supporters of social reform. McGowan regards the rapid institutionalization of advocacy as a component of casework practice to have been affected by three dynamics. First, the evolution of ego psychology, general systems theory and ecological theories contributed to practitioners becoming more aware of the impact of the environment on the individual as well as the effect of environmental change efforts on the individual’s self-image and level of confidence. Since it became apparent that availability of resources enhanced independent functioning, social workers advocated for access to necessary resources. As a



second influence, McGowan notes that the body of knowledge on organizational intervention and conflict resolution developed by community organizers in the 1960's and 1970's proved invaluable to direct service practitioners in their advocacy on behalf of clients. The third factor thought influential on the evolution of advocacy is the development of service quality monitoring systems by various governmental agencies in the 1970's. These initiatives provided public sanction and funding for what were termed 'advocacy services' and thus both broadened and legitimized advocacy as a component of case management (*p. 91*).

## **CHARACTERISTIC ELEMENTS OF ADVOCACY**

Advocacy is characterized by a number of component activities or dynamics such as communicating client needs to others, seeking a resource or entitlement from those in control of them, challenging obstructive processes and mediating with support systems. The common issue of advocacy for all social workers is the active pursuit of social justice for all clients and communities. As our profession has increasingly focused on client autonomy and empowering individuals and communities, our professional goals emphasize providing the means for clients to take responsibility for self-advocacy (*Gitterman and Germain, 2011; Wise, 2005*). While we may still attend a team meeting and speak up about the client's need for home care services upon hospital discharge, we also encourage the client and family members to state their needs directly to health care team members. If necessary, practitioners model and rehearse the process of making calls, writing letters, seeking meetings and other ways for clients to approach topics and advocate for themselves. This shared responsibility for advocacy is equally true in larger systems, as we represent communities' needs for improved access to health care services, help community members advocate and provide examples of what is needed. Our present text provides clear evidence of such effort in a broad array of contexts.

In health care settings the patient's voice is not always readily heard, and as patients and families cope with and adjust to illness, treatment and care, for many of them it is not easy to feel confident enough to ask questions, raise concern about what they are experiencing or express their feelings and wishes. As social workers become aware of what patients are coping with, they are well positioned to assist with communication of their needs to other members of the health care team and to support patients in recognizing the importance of making their experience known to the team.

Social workers who are employed by health care settings may find themselves when advocating for clients facing dual imperatives for action. While they have a primary obligation to serve the interests of the clients, advocating for them or supporting the client's self-advocacy, they also have allegiance to the agencies/or hospitals that employ them and expect their commitment to the organization. Thus, the social work advocate must find ways to balance the responsibilities of the profession and its code of ethics, norms and standards (including loyalty to the employing organization) together with a primary commitment to the clients and communities being served. In advocating for clients and communities, we need to be respectful of the power and potential of individuals and groups to make their voices heard and their needs known.

## CAUSE ADVOCACY: EXAMPLES OF SOCIAL WORK AT WORK

Schneider and Lester (2001) define “*cause advocacy*” as “promoting changes in policies and practices affecting all persons in a certain group or class” (p.196) and suggest that such action may be required when problems result from the inability of a patient or client to change or influence their circumstances. Citing Michelson (1995), they note that cause advocacy also reflects social work’s fundamental commitment to a “person-in-environment” perspective by virtue of the profession’s efforts to modify conditions that have a negative impact on the patient. In that sense, cause advocacy is viewed as an extension of client advocacy.

Cause advocacy is predicated on “mutuality”, the basis of which is the social work principle of “beginning where the patient is.” It requires the change agent, in this case the social worker, to understand what constitutes the patients’ needs and then to partner in planning, initiating and evaluating any services developed in response to those needs. To the extent feasible, those for whom the services were developed should be engaged from the onset so as to empower them in meeting their own needs. It further is crucial that care be taken in program design to recognize risks and potential backlash should scarce resources be appropriated for one cause by taking them from others. To that point, communication must be initiated and maintained in such a manner that all parties are made aware of the intended action and have opportunities to provide input into the process.

Communication should clarify the basis for why change is being initiated (problem identification) and then propose specific, implementable solutions to the concern(s). Understanding and prioritizing the real issues prompting a change comes from communication with those most affected. That communication includes not only the patient population in question, but decision makers in the organization and community at large who would be instrumental in the successful rollout of any proposed change. To gain support of the latter group means that social workers (and/or others) proposing change must be cognizant of the needs, constraints, priorities and concerns harbored by decision makers, as well as any laws and regulations that may impact on the implementation and operation of a proposed program. Recognizing such factors will better link strategies and tactics to those resources needed for change. It is here that historic social work skills in situational analysis, interpersonal communication, group work, collaborative planning and pragmatic leadership pay dividends.

Examples of successful cause advocacy constitute the basis for this text. Repeatedly, our authors demonstrate the effective use of advocacy in health care social work practice. *Johnstone* focuses on the dramatic change instituted in nephrology services as the result of reconceptualizing and repositioning social work practice to meet the multi-faceted needs of an expanding dialysis patient population. In identifying means to enhance the quality of life for patients and families, the creativity and global perspective of social work personnel led to unprecedented benefits to the provider organizations as well, constituting a true “win-win” situation. Persistence and dedication to advocating for this population was necessary to overcome initial resistance and the predictable concerns that arise when major change is introduced in an organization. Careful efforts at interdisciplinary team building contributed to positive patient outcomes while securing the long-term operational support needed to maintain new service structures.

Yet another fundamental philosophic and operational service shift evolved from the advocacy efforts of social work at the Mt. Sinai Health System in New York, New York. *Monti* and *Rosner* detail the intensive efforts undertaken by that organization to develop a health home program consistent with the Patient Protection and Affordable Care Act of 2010. In this instance, a large comprehensive network of twenty-two community agencies needed to be developed, including all data exchange and provider agreements along with policies/procedures, payment methods, clinical workflows and related provisions such that forty personnel could provide care to three thousand patients using new Federal service guidelines. Social work functioned in a highly visible lead role in both the creation and subsequent operation of this complex system, with the authors being established as co-directors of the new program.

Cause advocacy on behalf of an identified population was also clearly put forth by *Hedlund* in her efforts to initiate systematic program changes addressing the psychosocial needs of cancer patients and families. The notion of “mutuality” in advocacy emphasized by *Schneider* and *Lester (2001)* is underscored in this instance by the extensive collaborative negotiations necessary within the health system to conceive and implement a major shift in patient care operations. In a parallel example, *Fattore* and *Vega* highlight how identification of problems associated with treating emergency department “super-utilizers” led to advocating for service changes that reduced otherwise inappropriate emergency room visits by 81% and decreased admissions by 86% during one year in a large-scale Pennsylvania health system. Again, social work was actively engaged throughout the process and became viewed even more clearly for its impacts on this patient population.

Military service and exposure to combat presents severe psychological and physical challenges to troops, with veterans at particularly high risk of both post-traumatic stress disorder and traumatic brain injuries. Concern about the implications of these conditions on the sexual and the mental health of veterans became the catalyst for advocating new methods of holistic patient and family-centered care. In his chapter on interventions introduced at the Walter Reed National Military Medical Center, *Rodgers* outlines the advocacy steps leading to changes in assessment, counseling and education of “wounded warriors” and their families. Social work played a consistent role in problem identification, planning, support lobbying and implementation of new programs that may serve as the benchmark for expansion throughout the military service.

*Crombie* and *Ferry* provide another significant example of social work advocacy through their efforts to conceive and implement a medical respite program for homeless patients served by a major health system in Connecticut. Those efforts not only addressed patient needs, but by reducing inappropriate (and expensive) service use benefitted the health care provider system.

Collectively these authors demonstrate through the positive patient and organizational outcomes of their efforts that advocacy constitutes a fundamental component of health care social work practice. Simultaneously dealing with particularly needy patient populations and large-scale, complex health provider organizations, the authors’ experiences serve as a catalyst for others to embark in advocating within their own settings. The clear and proud history of the social work profession continues on in such efforts, while the challenge of a rapidly evolving

health care environment offers seemingly endless opportunities for the profession to effectively apply itself as a change agent.

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# **NEPHROLOGY SOCIAL WORK: THE GRASSROOTS ADVANCEMENT OF A SPECIALIZED FIELD**

*Stephanie Johnstone, LCSW*

## **INTRODUCTION**

This chapter highlights the innovation, leadership and patient advocacy efforts of social work in the field of nephrology. It discusses the underlying issues associated with dialysis and the factors affecting both patients' quality of life and utilization of health care services. Social work is noted for its dramatic impact on identification of these factors and active role in reconstructing service delivery to better promote patient health and resource use. The catalysts for change included the broad range of patient need, new legislation and modified reimbursement methodologies, corporate re-evaluation of organizational processes and a proactive social work stance focused on more effective patient care.

## **THE HISTORY OF DIALYSIS**

On March 9, 1960 Dr. Belding Scribner created the first artificial access to perform hemodialysis. This marked the beginning of a permanent treatment option for those with kidney failure. The "Scribner shunt" was surgically placed in to a patient on that day in 1960. The patient who would have normally died within a few weeks went on to live for another 11 years. In 1962 the first outpatient hemodialysis facility was opened in the basement of Swedish Hospital in Seattle. In November 1962, Life Magazine did an expose on the "Life and Death Committee" that was formed to either accept or deny candidates for hemodialysis, based on their medical condition and their capacity for psychological, social and financial rehabilitation. Patients were required to have the funds to pay for three years of dialysis treatment which, in the 1960s, was \$30,000. The "committee", which was held anonymous, consisted of a surgeon, a physician, a member of the clergy, a labor leader, a housewife and other members of the community. Many patients were simply too young, too old, too poor or had too many other illnesses and thus were denied this this costly life sustaining treatment (1, 2).

In 1971 Congress and the White House were debating national health insurance. Shep Glazer, a candidate lucky enough to have been selected to receive hemodialysis, underwent a brief dialysis treatment in front of a congressional committee. His goal was to demonstrate how hemodialysis could remove the toxins and fluid from his body that his damaged kidneys could no longer remove and allow him and others to live with kidney failure. Shep was dedicated to the cause for the many Americans who were diagnosed with this catastrophic illness who could not afford to pay for treatment to extend their lives. On October 30, 1972, President Richard Nixon signed the law that extended Medicare coverage to people with kidney failure. On July 1, 1973, Medicare began to confer automatic eligibility on almost anyone diagnosed with ESRD. For the first time in history, whether an American was less than 5 or 65 years of age, the federal government would cover their cost of care if their kidneys failed. The kidney community - hospitals, nephrologists and renal professionals moved forward to accommodate a growing

number of persons with ESRD across North America. This growth would soon be determined an “epidemic” due to aging of the baby boomers, and their incidence of diabetes and hypertension, which impacted the diagnosis of End Stage Renal Disease. By 1980, Over 57,000 patients were treated for kidney failure. By 2012, the population had grown to nearly 637,000 patients in the US (2, 3).

As the epidemic progressed, so did the psychosocial diversity of the ESRD patient requiring dialysis which now included the very young, the very old, all socioeconomic levels, some with and others without family support. Patients with chronic mental illness, substance use and terminal medical conditions were offered hemodialysis to sustain life. The field of nephrology social work sprang into action and evolved to meet the needs of this growing and diverse population.

## **ESRD REGULATIONS AND THE STRUGGLING FIELD OF NEPHROLOGY SOCIAL WORK**

The first regulations governing dialysis clinics, and social workers in those clinics, were published on June 3, 1976. While the federal regulations for nephrology social work were seemingly well-defined and focused on rehabilitation and the emotional adjustment of the hemodialysis patient, the epidemic influx of the dialysis patients into community dialysis clinics was powerful and disorienting. Masters level social workers eventually found themselves focusing on obtaining emergency resources in both for-profit and non-profit dialysis organizations and providing the majority of their service time to 20% of the population that remained in crisis. The scope of the average social worker’s day-to-day practice focused on securing insurance coverage, transportation services and emergency funding for housing, food and medication. Little time remained for the rehabilitation and counseling needs of the other 80% of hemodialysis patients in the clinic. Depressive symptoms, anxiety, family dysfunction, and employment needs were attended to less and less. These more silent barriers to wellness remained and continued to impact both the quality and cost outcomes of the dialysis industry.

As the epidemic kept growing, this skewed system of social work service delivery worsened. Organizations narrowed their expectations for MSW level services and many MSWs left the field of nephrology social work, unfulfilled by the devaluing of their training and the inability to get to the underlying needs of their caseloads of 125 patients or more. As the epidemic continued, untreated psychosocial problems grew louder. Non-adherence to prescribed treatment worsened the clinical outcomes. Publications focused on how the United States, one of the leaders of industrialized nations, had one of the highest mortality rates for hemodialysis patients (4, 5). A major contributor to this high mortality rate was a growing number of patients who were not attending their scheduled treatments or following their fluid restrictions, both of which led to congestive heart failure, hospitalization and death. This non-adherence to treatment and lack of self-management came into sharp focus. The industry turned to nephrology social work to help with these struggling and costly patients, but social workers had little time to develop intervention models or spend sufficient time with these high risk patients due to their focus on providing emergency resources. The industry had also grown entirely confused as to

how to deploy the skills of the MSW and feared any change in social work service delivery which could result in less focus on ensuring insurance coverage and resources for patients.

Additional industry problems presented due to the lack of time to address the psychosocial needs of the patient. The incidence of patient disruption in the dialysis clinic was rapidly increasing (6). The dialysis teams had little available time with their nephrology social worker, who was the key person who could provide them with skills to meet the growing challenges of mental illness and substance abuse in the open floor treatment environment. Demanding and disruptive patient behavior was also, in part, related to the lack of social work time to attend to the underlying mood disorders that were prevalent in up to 40% of the population. Depression was impacting mortality rates and referrals to outpatient mental health providers were not successful (7, 8). Few patients followed through with seeking outpatient mental health due to the existing appointment burden, fatigue and lack of transportation and out-of-pocket expenses (9). The shrinking number of available organs due to the epidemic numbers of patients on the transplant waitlist extended the waiting time for kidney transplantation, further increasing patient frustration (10). Social workers had little time to design rehabilitation plans for the many patients awaiting a kidney transplant. Few able-bodied patients sought or returned to work due to the lack of rehabilitation services. Most patients did not even return to previous activities on non-dialysis days, increasing a sense of burden and disempowerment in the population at large. Despite the availability of home dialysis to promote rehabilitation and a more normal lifestyle, the vast majority of patients chose in-center hemodialysis and remained in a state of emotional and physical dependency on their care providers (11). Social workers had little time to promote the benefits of home dialysis therapy. Most patients did not even realize it was an option.

## **THE NEED FOR A NEW MODEL OF NEPHROLOGY SOCIAL WORK PRACTICE**

These growing needs and tensions provided the catalyst for social workers across the nephrology industry to collect and organize change efforts through their professional organization (the National Kidney Foundation Council of Nephrology Social Workers). Although the industry was narrowing its expectations of how nephrology social workers should be utilized, social workers were hopeful that new approaches could be deployed to manage these multiple, psychosocial problems. Judith Kari became the first chairperson of the Council of Nephrology Social Workers (CNSW). The organization continued to grow in numbers and became the hub of nephrology social work reform. Committed social workers stepped forward, year after year, to continue the strong leadership Kari had started for the council. Their goals focused on establishing standards for nephrology social work and developing professional training for the large numbers of nephrology social workers that were needed to manage the ESRD epidemic.

In 1997 a group of social work leaders in CNSW gathered to construct the “Outcomes-Driven Nephrology Social Work Model” for the industry (12-14). This model directed training to nephrology social workers across the nation. The training focused on the reorganization of a social worker’s services to have more time to address clinical barriers to survival and wellness,



such as depression, anxiety, family stress and non-adherent behavior. New intervention models to address these clinical barriers were designed. The National Kidney Foundation Spring Clinical Meetings became the training ground for full-day workshops. Social workers who attended those workshops each year returned to their local chapter meetings to provide outreach to social workers across the country. It is estimated that over 1000 social workers have been trained at those meetings and returned to their local CNSW chapters to gather grassroots support for the model. Nephrology social workers across the country clamored for more training in the model, but the industry was struggling to reform. Many social workers that were trained returned to their clinics frustrated with the continuing expectations that they focus primarily on insurance and emergency resource referrals. They grew disempowered in the reform movement. The social workers that were able to move into the new model, however, were starting to improve patient outcomes and demonstrating the effectiveness of the model (15-18). Their managers were noticing and listening. The industry was desperate for help with the patients who were struggling with self-management. If something was working, it needed advancement. Top industry leaders and social workers were joining forces more and more to promote the outcomes-driven model of nephrology social work practice.

## **SOCIAL WORKERS ASSUME LEADERSHIP POSITIONS IN LARGE DIALYSIS ORGANIZATIONS**

By 1998, large dialysis organizations were recognizing the importance of outcomes-driven nephrology social work practice in their organizations. Corporate social work positions were developed in the two largest dialysis organizations in North America. Those leaders moved quickly to develop job descriptions, social work policies and to integrate new models of social work intervention that were so needed. These corporate social work leaders were invited to a permanent seat at the senior leadership table, where nurse leaders had previously made decisions regarding social work services in the organizations.

Between 1998 and 2000, those corporate social work leaders began to promote regional social work leaders across the country. In the years that followed, regional social work positions were developed, with these regional social work leaders providing training and oversight to up to 60 social workers. This expansion of leadership was pivotal in the advancement of nephrology social work in that more progressive models of social work intervention could be designed, deployed and outcomes measured quickly. With social work leaders at the corporate level, data demonstrating the impact of social work interventions on corporate quality goals could be published and presented routinely at the organizational level (19-21). By 2008, following a ten year period of increasing social work caseloads and the consideration of hiring bachelor level instead of master's level social workers, dialysis organizations were starting to view the MSW as a new, untapped resource for the changing road ahead in medicine.

In 2005, the Centers for Medicare and Medicaid Services had proposed its second set of regulations. These new proposed regulations acknowledged the growing literature connecting psychosocial barriers to patient survival and hospitalizations. The CNSW outcomes-based nephrology social work model had demonstrated effectiveness in literature published by key

leaders from the Council of Nephrology Social Workers. While in the 1976 regulations CMS had directed a clinical focus for the MSW, in the proposed regulations, CMS further defined the specific areas of assessment and counseling the MSW must provide to all dialysis patients. At the National Kidney Foundation Meeting that year, hundreds of nephrology social workers gathered to submit public comment on the proposed regulations. Their comments focused on qualifications for social workers as well as assessment and plan of care requirements addressing patient psychosocial needs. The final set of ESRD Medicare conditions for coverage required that all dialysis patients (aside from a few exclusions) be offered an age-appropriate health related quality of life (HRQOL) survey (22). Problems identified by that survey were to be addressed by the interdisciplinary team, including the social worker. Patient rehabilitation goals, difficulty adjusting to illness and barriers to following the treatment plan (self-management) all required social work intervention, outcomes measurement and trending. The metrics-focused nature of the new regulations supported the outcomes-driven model of social work practice. While the new proposed regulations did not specify a ratio of patients-to-social worker to address the overwhelming number of emergency services they were providing, these new requirements would drive ESRD surveyors to regularly assess whether social workers were given adequate time to provide counseling in these areas to all patients. The final regulations complemented the industry's concern over psychosocial barriers that impeded patient and facility level outcomes. Once finalized in 2008, these regulations became a second catalyst for nephrology social workers and dialysis organizations to engage in new, more strategic models of nephrology social work care (23).

## **EXPANSION OF EVIDENCE-BASED NEPHROLOGY SOC WK PRACTICE**

By 2010, dialysis corporations were calling for clinical social work models that were reliable and reproducible on a large scale for promoting patient adherence. The increasing costs of hospitalizations for dialysis patients were of growing concern for both providers and payors. CMS “pay for performance” models of reimbursement were under development for dialysis providers (24, 25). If dialysis providers could not identify and address the root causes of avoidable hospitalizations, they could suffer reimbursement deductions. These deductions would be necessary to keep Medicare reimbursement sustainable against the epidemic of ESRD. The integrated care movement was forming, where all players in the field moved to the top of their training to form evidence-based models of care delivery. Provider networks and ACOs were organizing to look at care coordination opportunities in the field of ESRD (26). Seated at the table with advancing skills, the nephrology social worker became a key player in stabilizing models of psychosocial care that could promote patient adjustment to illness and adherence to the treatment plan, both of which could reduce the costly hospitalizations in the ESRD population (27).

Social work leaders perceived this as a critical time for the field. Tools from the CNSW Outcomes Driven Practice Model were effectively addressing the psychosocial barriers that could impact mortality and hospitalizations. Social workers, when probing into the lives of the non-adherent patient, could see that these patients were committed to their health and they understood their treatment plans. These patients could “repeat back” their understanding of how

important it was to attend all of their dialysis treatments, restrict their fluids and follow their dietary and medication regimen. They knew how quickly any deviation from the treatment plan could lead to a hospitalization episode. They were, however, not coping well with their lives on dialysis. When social workers began to survey the patients to seek an understanding of the struggle of the non-adherent patient, themes such as “I just can’t handle it”; “I am too tired and I don’t have enough support to help me manage”; and “I am too stressed by other things going on in my life” and “I just don’t know if I want to do this anymore” surfaced as primary barriers to attending their dialysis treatment and managing other elements of their self-management. It was critical that nephrology social workers deploy the interventions they now had to effectively reduced distress in the life of the struggling hemodialysis patient.

## **INNOVATIVE SOCIAL WORK SERVICES**

Large dialysis organizations moved quickly forward in the new value-based medical environment. Fresenius Medical Care began piloting tools from the National Kidney Foundation Outcomes Driven Nephrology Social Work Program alongside a toolbox of their own to reduce the number of patients who were missing their hemodialysis treatments. These patients were risking their health and survival and contributing to the concern about costly, avoidable hospitalizations. The interventions focused among other things on managing depressive symptoms, adaptation to a dialysis lifestyle, rehabilitation, and mobilizing social support (16-21; 28-30).

In 2011 Symptom Targeted Intervention (STI) was developed by nephrology social worker Melissa McCool to further address depression in dialysis patients (31). While depression intervention tools were provided in the CNSW outcomes driven nephrology social work model, STI offered additional training and tools that could be utilized by nephrology social workers in the dialysis clinic. STI focused on a brief, more “targeted” model of intervention that could allow nephrology social workers to provide intervention while juggling the other demands in their day-to-day workflow.

A seasoned group of nephrology social workers formed an independent workgroup known as “The Forum for the Advancement of Nephrology Social Work” to provide training on STI to volunteer social workers invited from all dialysis organizations. McCool created a manual to train the pilot Social Workers and a DVD was also created to support this training. These materials were distributed to 47 social work volunteers across 17 states. Following the initial training pilot, social workers from multiple dialysis organizations provided feedback on how patients were responding to some of the clinical interventions McCool designed. They shared their quality improvement outcomes in aggregate format as well as their experience of using the STI tools. The results were impressive. After six weeks of intervention, patients had improved health-related quality of life scores and reduced depressive symptoms. Social workers were recommending the STI tools as something that were easy to deploy to further assist all nephrology social workers in managing depressive symptoms in their dialysis patients. The description of the pilot and its results were published in the spring of 2011 in *Nephrology News and Issues* (32-33). The STI tools became available for purchase to all nephrology social workers soon after that pilot and were later expanded to guide social workers in other health care fields. For the first time, social workers in smaller dialysis organizations and independently

owned clinics across the country could access skill advancement training. This was especially important for those nephrology social workers that could not attend either the annual NKF-CNSW meetings or local chapter trainings to receive the CNSW Outcomes-Driven Nephrology Social Work training.

## **THE BROADER REORGANIZATION OF SOCIAL WORK SERVICES**

As the CMS conditions for coverage continued to require social work services to provide clinical counseling and rehabilitation services, and the reimbursement environment continued to drive the need for these services to control the escalating costs of the ESRD epidemic, it became time for social work leaders to propose a more formal reorganization of nephrology social work services in their corporations.

The scope of services that social workers were providing in their daily workflow came under formal review at Fresenius Medical Care. Caseloads were stabilized, and in some cases, reduced. Time studies were completed. Sixteen areas of social work service were identified that did not require the skills of a master's prepared social worker (MSW). These included tasks such as data entry of demographic information into computer tracking systems and helping patients arrange for a dialysis treatment when travelling to another state. It was determined that if these sixteen tasks could be transitioned from an MSW to a clinic facility secretary or absorbed by another team member, social workers could retrieve eight hours per week to deliver more intensive intervention to patients who struggled with self-management to reduce avoidable hospitalizations. Corporate and regional social work leaders worked with top level managers to drive the transition of these tasks at Fresenius. Resources were scarce due to changes in the medical reimbursement environment. Front line teams had to reorganize without additional staff.

## **BUILDING INTERDISCIPLINARY TEAM SUPPORT FOR SOCIAL WORK REORGANIZATION**

If you asked most interdisciplinary team members : “Do you think we should give the social workers more time to work with patients who are struggling with self-management?”, most would answer “Yes, but what about nursing, and nutrition services? We all need more time too.” It became imperative that social work leaders be prepared to speak to managers and field teams, during this time of scarce resources, to demonstrate the benefit of reorganizing social work services for all team members. Social workers needed to have conversations with administrators about how improving patient adherence would reduce hospitalizations and create better partnership for the hospital and dialysis providers to reduce the risk of the looming reimbursement cuts. It was important for nurses, technicians and secretaries at the dialysis facility to realize how helping patients attend every treatment would help them provide safer and more efficient treatment in their daily workflow. It was important for the nurse managers to see the new counseling tools and interventions to understand how they work, and for the social worker to explain how using these tools and interventions would improve the overall quality in the clinic's quality assessment and performance improvement (QAPI) meetings each month. Social workers had to point out that helping to reduce patients' emotional distress could reduce

and patient-provider conflict episodes in the outpatient dialysis clinic, which makes the workplace a safer and more pleasant environment for the interdisciplinary team. Finally, social workers had to learn business models. They needed to work alongside our senior management to learn how improving dialysis attendance and fluid management could reduce turnover and staffing costs and help support the organic growth goals of the organization. Reorganizing social work services was a win-win for everyone in the dialysis industry and social workers needed strong skills to have all of these crucial conversations.

Corporate social work leaders created evidence-based slide presentations demonstrating the link between psychosocial barriers, quality outcomes and hospitalizations. Interdisciplinary team members and the organization-at-large had gaps in their knowledge regarding the education and training of the MSW, who was often the team member with the highest level of education second only to the physician. Every social worker was challenged to grow their teaching and presentation skills to describe their scope of education and practice. Each social workers was trained to review the types of interventions they could deploy to improve quality of care and organizational outcomes. These included cognitive-behavioral, mindfulness, psycho-education, group and family counseling skills. Corporate social work leaders trained regional social work leaders who then trained, with aligned slide presentations, over 2000 individual social workers. Social workers were also professionally coached by their leaders through this period of change. It was important they did not personalize any negative team reactions to the transition of task as it occurred. Instead, they needed to expect all types of reaction to change in an organization that had limited resources in the changing reimbursement environment. Social workers were well prepared to begin helping their team members with training and education and their at-risk patients with more intervention. With time, facility teams accepted the task transitions. Secretaries, patient care technicians and even nurse managers stepped up to absorb the sixteen administrative tasks that would provide social workers with additional time to deploy an innovative program to improve patient self-management. In turn, they wanted a solid social work program that demonstrated outcomes.

## **SOCIAL WORK COMMITMENT TO CONTINUING EDUCATION AND ADVANCEMENT OF SKILL SETS**

Additional time and training was not enough to advance the field of nephrology social work toward improved outcomes. While most social workers rapidly embraced the additional time to deploy the clinical counseling skills they had developed from the NKF program and the STI model, many social workers were nervous about, and resistant to, the new expectations to deliver clinical social work interventions. Looking back, they had spent most of the previous decade providing emergency resource referral and completing the sixteen administrative tasks which had left them feeling rusty in their ability to perform root cause assessments and counseling interventions. Social work leaders identified that the social workers who lacked confidence were the social workers resistant to advancing the field. Those leaders had to address these ground level fears with patience, confidence building and additional support. By 2013, over 2000 social workers across Fresenius Medical Care (the largest provider in North America) had received live two-day training from their division lead social workers, followed by frequent refresher training, webinar grand rounds calls and individual support to assess and advance their

clinical skills. By 2014, all social workers across DaVita, the second largest dialysis provider in North America, received intensive training and follow up support from Melissa McCool (the author of Symptom Targeted Intervention) to advance their clinical counseling skills. Hemodialysis patients across North America were receiving social work services that would decrease distress, improve self-management skills and reduce costly hospitalizations.

## **RESEARCH, SCIENTIFIC PRESENTATION AND AWARDS**

Social workers at both large dialysis organizations collected data and continued to present abstracts and publish positive results from their new intervention models. In 2012 Fresenius Medical Care was awarded the prestigious *Modern Healthcare Spirit of Excellence Award* for their program for patients struggling with self-management, which became known as the Social Work Intensive (34). The program utilized Fresenius-designed social work intervention tools combined with CNSW and STI tools. In 2014 Fresenius was awarded the “Outstanding Poster Award” at the NKF Spring Clinical Meeting for data demonstrating a significant reduction in missed treatments and improvements in patient health related quality of life scores (an indicator that is predictive of hospitalizations and death) (35). That same year, Fresenius was invited to present both an oral presentation and an abstract at the 2014 American Society of Nephrology (ASN) Clinical Meeting in Philadelphia. The focus of the presentations were the Fresenius Medical Care social work data demonstrating improved treatment attendance and fluid management outcomes, including decreased fluid related and all-cause hospitalizations (36, 37). In 2014, DaVita Kidney Care was invited to present an abstract on their data validating the use of STI to reduce depressive symptoms (38). In 2015 DaVita was awarded a “Top Poster” award from the NKF Spring Clinical Meeting for data that demonstrated the impact of Symptom Targeted Intervention (STI) on reducing missed treatments (39).

News of these awards and outcomes travelled across the industry. The Wall Street Journal and the renal trade publications (40, 41) featured the awards and the new model of nephrology social work intervention to improve quality outcomes for ESRD patients. Nephrology social workers in smaller organizations had the formal data they needed to fight for reorganization in their organizations. Today, the reorganization of nephrology social work in smaller dialysis organizations is in the early stages of development.

## **MAINTAINING ADVANCEMENT OF NEPHROLOGY SOCIAL WORK**

While social work advocacy and partnership with top level leaders in the organization created the initial environment social workers needed to advance the profession, those efforts needed mechanisms for remaining accountable to ensure the changes did not default back to the earlier, less progressive models of social work service delivery for the organization. It was a continuing threat that social workers would be pulled back into, or volunteer to resume, the sixteen tasks that were transitioned to other team members at Fresenius. Each time the senior managers and social work leaders witnessed this occurring, it was discouraging. The effort it took to “re-transition” those tasks back to other team members drained valuable resources. It became clear that the organization needed a monitoring mechanism to prevent that from

occurring. Fresenius senior managers helped social work leaders develop a tool called the Transition Task Report, which was to be completed monthly by the nurse manager and the social worker with regard to the current assignment of the sixteen tasks. Based on their “task transition” the social worker was assigned productivity in the Social Work Intensive program. Nurse Managers became accountable to top leaders for making sure that tasks did not relapse back onto the social worker, in an effort to enroll as many at-risk patients as possible in the SW Intensive program each month. If social workers were fully task-transitioned, the patients, the facility and the organization at large would greatly benefit from a fully productive program designed to improve quality and organizational growth outcomes. This monthly accountability measure, overseen by top leadership, allowed the change in the social work scope of service to stabilize. Nurse managers began to partner with their social workers to help them guard their time in the interest of these outcomes.

Accountability measures also had to be taken to ensure social workers embraced the change in their service delivery and remained committed to their own professional growth and advancement of their counseling skills. Social work leaders and nurse managers needed a way to ensure that social workers were guarding their time from the urgencies of day-to-day case management to deliver the program delivered to the patients struggling with their self-management. A monthly “productivity formula” was designed. Lead social workers in each region became responsible to report on their regional social work productivity, manage social work under-productivity and overcome any environmental barriers that fed that underproductive status. These barriers included covering social work vacancies that reduced time in their own clinic to run the program. Social work leadership skills grew even stronger and their professional model for accountability gained respect from the organizational leaders.

A positive consequence of the monthly SW productivity call was that top leaders began to more fully understand the day- to-day barriers that social workers had in their service delivery. Social work turnover gained more organizational attention and support. Another unexpected consequence was that this “accountability” model improved the motivation of the more resistant social workers to advance their skills. They did not want to be on the “under-productive list” with their social work services. To leaders, this was one of the most surprising, and perhaps disappointing discoveries of the advocacy movement- that social workers, themselves, might need consequences to enhance their commitment to professional growth. Some social workers actually left the field, declaring their refusal to advance their master’s prepared counseling skills. Despite this finding, the growth and advancement of the nephrology social work field did, indeed, occur and leaders were able to celebrate the advancement of a profession, regardless of what motivated the social workers to accomplish it. In fact, social work leaders noticed that, as social workers advanced their clinical counseling skills, they almost unanimously appeared more professionally confident and proud of their profession again.

## **CONTINUING ADVANCEMENT OF THE FIELD**

As the medical field continues to undergo sweeping changes in the way it delivers care and the methods by which it is reimbursed, nephrology social workers are continuing to develop responsive social work models. As new nephrology social workers begin to practice in this field,

one of the most important skills they need to grow quickly is the ability to teach. In keeping with a systemic view of nephrology social work, there are several clients served by the social worker that require education. First, as the social worker delivers on-site counseling services the ability to provide coaching and training to help the patient utilize tools to reduce distress is a key skill. Second, the interdisciplinary team, that is trained to approach the patient in a linear fashion, will need training on the larger view of the patient. The MSW person-in-environment model will help the treatment team develop more effective relationships with patients as health care providers. Third, as top leaders make decisions regarding resource allocations and assign tasks within the organizations, the social worker at all levels in the organization will need to deliver formal and informal presentations at management meetings and quality improvement forums. These presentations will need to define the scope of current services and the value of what those services offer as well as time-studies to inform careful decision-making regarding the scope of social work services in the dialysis organization. Effective teaching and presentation skills are critical for the nephrology social worker to continue to advance their profession.

## **QUALITY OF LIFE: PATIENTS REAP THE BENEFITS OF SOCIAL WORK ADVOCACY**

Over 500 patients were included in the data presented at the 2014 ASN meeting in Philadelphia. As one looks at the data, it is hard to ignore how the advancement of nephrology social work will impact the health and quality of life of the patient with ESRD. As one patient put it: “When I worked with my social worker to improve my quality of life I realized that I wasn’t done living. I just didn’t know how to get back to my old self again. Living on dialysis is hard. But with the tools I am now trained to use, it is less hard. I have goals again. I feel like somebody again. And I want to take better care of myself because I deserve that.”

As nephrology social workers provide psychosocial services to the growing number of ESRD patients ahead, they can feel proud of their advancements. Their services have been responsive to both patient and industry needs. In addition, they have learned how to design, deliver and measure the effectiveness of their services in improving the health and quality of life of patients while reducing the costs of ESRD care. The patients, the dialysis providers, the industry and the federal and private payers of this costly chronic illness will all benefit from the advocacy efforts of nephrology social workers.

*The author would like to acknowledge all social work chairpersons since the 1973 establishment of the National Kidney Foundation Council of Nephrology Social Workers; the members of the Forum for the Advancement of Nephrology Social Work, the corporate and regional social work leaders from Fresenius Medical Care and DaVita Kidney Care, Melissa McCool, Mary Beth Callahan, Beth Witten and the over 4000 nephrology social workers at DaVita, Fresenius and other dialysis organizations that helped to advance the field of nephrology social work.*



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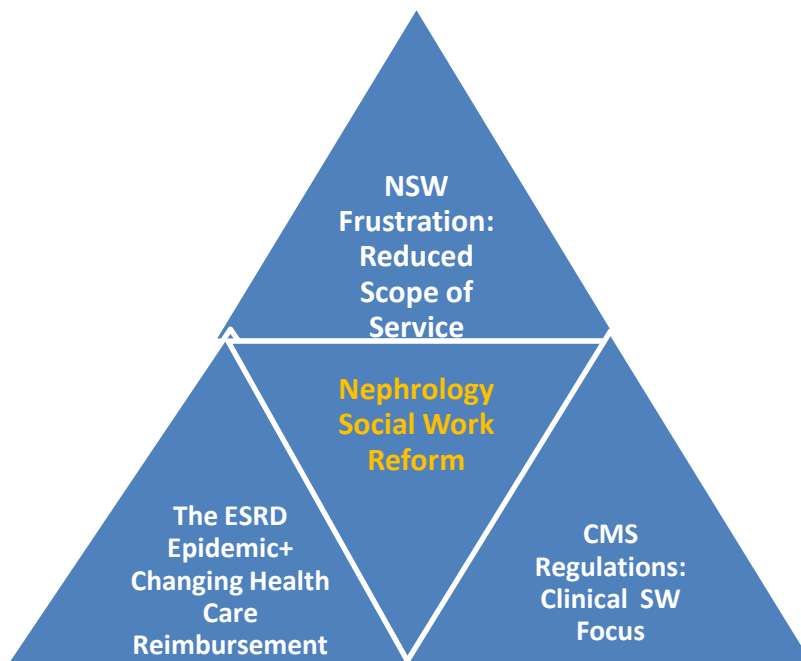
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**TABLE 1**

**The Environmental Factors that Mobilized Nephrology Social Work (NSW) Reform**



# **SOMETHING FROM NOTHING: THE DEVELOPMENT OF A HEALTH HOME PROGRAM IN NEW YORK CITY**

*Kristina Monti, LCSW and Arielle Rosner, LCSW*

## **INTRODUCTION**

In 2012, the Mount Sinai Health System was designated as a New York State Department of Health (NYSDOH), Health Home. The Health Home (HH) program was initiated through section 2701 of the Patient Protection and Affordable Care Act in an effort to reduce preventable hospitalizations and emergency department visits by Medicaid recipients. Through ongoing, community-based care coordination, the HH program attains this goal by linking patients to community based healthcare, while addressing any and all psychosocial barriers that might impede the patients' overall health and quality of life. The Mount Sinai Health Home's designation was an opportunity for the authors to be involved in a new and exciting initiative that would benefit some of New York City's most vulnerable and needy individuals; however, this opportunity was also accompanied by enormous challenges which required various types and degrees of advocacy.

## **THE CHALLENGES REQUIRING ADVOCACY**

All lead HHs, once designated, had to build large and comprehensive networks of community based agencies that would provide care coordination services. Data exchange and subcontracting provider agreements, including payment and fee structure details, had to be negotiated and executed between the HH and the network provider agencies. Policies and procedures, payment methods, clinical workflows, and data sharing through various IT platforms had to be developed and implemented in order to get the HH network up and running. Additionally, the HH had to execute contracts with various Managed Care Organizations (MCOs), which required another set of workflows and procedures. Tackling these initial challenges was essential in building the foundation of the HH; these initial tasks and puzzles had to be completed and solved quickly.

Throughout a large and recently formed health system, the authors had to educate not only patients, but also healthcare providers about a program that was new and relatively unknown. Staff needed to be hired, office space needed to be secured, and patient identification and risk stratification techniques needed to be researched, explored, and developed. What were the best practices that were currently endorsed to serve a population who was largely underserved, disconnected from ambulatory healthcare, and who possessed various psychosocial issues and systemic barriers? Who were the correct persons to partner with and employ to lead this initiative, and what qualities did they need to possess to push this ambiguous new program forward?

The authors, who themselves left the comforts of their secure positions and took a chance on a new and unknown program, quickly had to strategize, partner and advocate to build something from nothing. This chapter discusses how, through advocacy and critical thinking, a program designation was transformed into a fully functioning lead HH, consisting of twenty-two sub-contracted community based providers, and forty employees, who are providing comprehensive care coordination to three thousand patients.

## **HEALTH HOME BASICS**

Before delving further into the various types of advocacy employed throughout the HH program development, it is important to understand the basics of the program and the population served. HH services are available for Medicaid recipients who have two or more chronic conditions, or one qualifying condition. In NY State, these qualifying conditions include HIV/AIDS or a diagnosis of a serious and persistent mental illness. These individuals must also have a demonstrated need for care coordination services. For example, they are high utilizers of the hospital or emergency room, are non-adherent with appointments or prescribed medications, or are generally very high risk from a psychosocial perspective.

Medicaid recipients can be assigned to receive HH outreach (with the goal of enrollment) by the NYS DOH, or they can be referred for the services by a member of his or her care team. The services are voluntary, and if the patient enrolls, he/she will receive holistic, comprehensive care coordination services from a community based agency or hospital employee. This care coordinator acts as a point person for the patient, connecting and collaborating with care team members and community support services to improve a patient's medical and behavioral health. The HH services provided by a care coordinator are categorized under the following core areas: comprehensive care management, health promotion, referral to community support services, patient and family support, and transitional care.

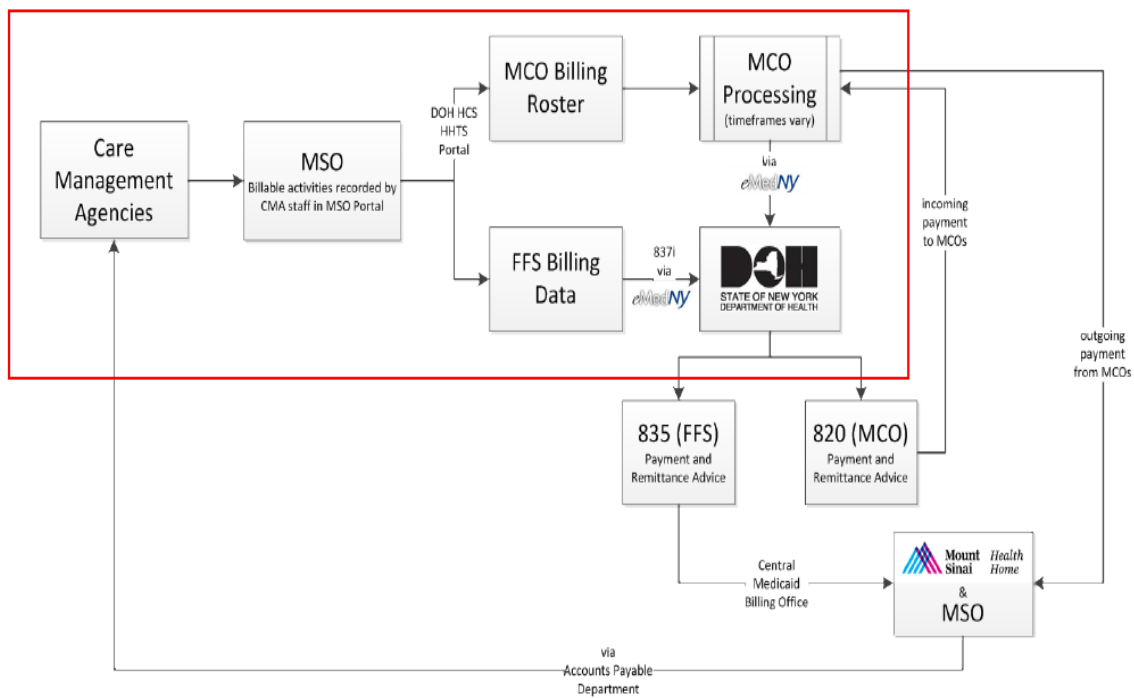
HH services are billable, as long as at least one intervention is completed with a patient or member of a patient's care team during every month of enrollment. The reimbursement structure is complex, as the information has to flow first from the care management agency to the lead HH, then to the State, the Medicaid managed care plan, and back to the lead HH. Once the lead HH receives the reimbursement, the payment is finally passed on to the community based agency that completed the service.

## **POLICY ADVOCACY**

The challenges in launching the HH program ranged from the very basic, such as securing office space and supplies, to the more difficult, such as recruiting, interviewing and hiring program staff, operationalizing payment to the community based providers, and working with lawyers to negotiate contracts. These larger scale tasks required the ability to secure funding and support from the larger institution. In order to accomplish this, the authors had to obtain the attention of what Jansson (2011, p. 381) refers to as "policy entrepreneurs." These are decision makers that assist in policy reform and program development through strategically

linking the goals of multiple programs together, securing support from other stakeholders and sponsors, and who can negotiate and bargain on the program’s behalf. In order to garner the attention of these key decision makers, the authors ensured they had a seat at the table from the very beginning of the designation process. This allowed for a visible presence and reinforced roles as the leaders of the program. Additionally, meetings were requested with anyone and everyone who expressed interested and could potentially assist in pushing the HH program agenda forward. Eventually, a Stakeholders Committee was formed, comprising of leaders within the institution from various departments, including finance, IT, behavioral health, medicine, population health, and social work. All parties represented different fields, with a different perspective and understanding of the role that the HH program could play for patients and for the institution. Having been involved from the beginning, all stakeholders have responded well to HH leadership’s advocacy, requests, questions, and needs throughout the two years of the program’s existence.

As the HH program rolled out, it quickly became clear the complex payment structure of the HH was not something that could be handled by HH leadership alone. As mentioned above, the billing structure involved many steps, many different organizations, and many technical requirements (*see chart below*).



In order to accomplish this very tall and complex task, it was evident that the DOH-required billing and tracking process needed to be outsourced. In order to get approval to do so, the authors held numerous meetings with various internal stakeholders, repeatedly explained the complexity of the billing and tracking process, and advocated for the advantages that an outsourced company could provide. Outsourcing was not the initial preference of the institution;

however, once the case was made, the HH secured approval and funding was provided. This was a huge step in formalizing the Mount Sinai HH's structure and functionality.

Similar advocacy with key stakeholders was a necessity outside of Mount Sinai. It was imperative to establish a presence as leaders in the HH community from the inception of the program. The authors had to engage and partner with leadership from community based organizations, existing care coordination programs, other lead HHs throughout the state, the Medicaid managed care plans, and the HH team at the State Department of Health in order to move the program forward. Whenever there was a meeting, conference call, or webinar held by the Department of Health, local/State/City agencies, or policy and advocacy groups, the authors ensured a vocal presence and strong representation.

Areas of policy advocacy over the last two years have included the complex billing process, the reimbursement structure and rates, the documentation requirements, and the timelines of new programs under the HH umbrella. The authors have advocated for the needs of the Mount Sinai HH, as well as the needs of the subcontracted community based providers. This initially was being done individually through scheduled meetings, written responses, and learning collaboratives. As the program matured, however, it became clear through the daunting and intensive requirements, that the lead HHs had no need to act as competing entities. Instead, the communication among the leads quickly became collaborative and unified. In 2014, a Health Home Coalition was created. The authors have taken a leadership role in this group, comprised of leadership from the HHs throughout New York State. Through this partnership, the momentum of advocacy has increased, and the lead HHs have a collective voice in recommending new standards, timelines, and best practices. HH leadership now have regular meetings with the Department of Health where regulations and policies of this new and ever-changing program are collaboratively discussed and written recommendations on behalf of the HH Coalition are made.

## **THE USE OF DATA AND IT FOR STRATEGIC DECISION MAKING**

After receiving HH designation, deciding where to focus efforts, and gaining support from key stakeholders, the authors developed proposals repeatedly to move the program forward. As mentioned above, one of the first proposals aimed to outsource the billing and tracking information that had to be reported to NYS DOH. That soon followed by proposals for new staff, a structure for stratifying and assigning patients who had the highest need, and for quality initiatives and policies/procedures to ensure that patients were being served effectively and appropriately. Partnerships and collaboration with the IT department and business/performance analysts allowed the program to justify needs and demonstrate effectiveness.

The authors quickly realized that the volume of patients that the State expected that each lead HH serve was larger than the community based organizations and the internal Mount Sinai HH staff could handle. A strategy needed to be developed to analyze and prioritize the patients who were being assigned to the program, and to ensure that they were then assigned to a care coordinator/agency that would best suit their needs. In brainstorming with the IT and data teams, an algorithm was developed to analyze the assignment lists from the State and determine which

patients were the highest utilizers of care, in which in- and out-patient settings, and with which organizations in the community. This allowed the lead HH to assign patients according to these factors, in the community in which they live, and to a staff member who was familiar with their chronic condition or their providers.

This information also allowed the Mount Sinai HH leadership to estimate the volume of patients well-known to the Mount Sinai Health System's practices, emergency departments, and inpatient units who would benefit from HH services. With this information, an internal staffing model was developed; using a specific caseload size, volume of assignments, reimbursement rates, and data regarding patient "loyalty" to specific areas of the health system, the leadership was able to demonstrate that the monthly reimbursement for HH services that the staff members were providing would cover their salaries and benefits. A team structure was created: for each caseload of patients, a social worker would take the lead responsibility for the patients (i.e. complete psychosocial assessments, develop care plans, and provide crisis and clinical intervention), and a care coordinator would support the social worker (i.e. assist with concrete services, and take the lead on lower risk patients). Once the model was developed, the authors were able to present the structure to the various areas of the hospital with a demonstrated patient need. The authors were also able to pass this financial model on to certain community based providers who expressed interest.

Similarly, proposals were made to the team leads for the electronic medical record of the health system in order to ensure that the data reporting requirements could be captured in the Social Worker/Care Coordinator documentation. Once that build was complete, the authors moved forward with setting up regular meetings with the interoperability team to develop a means for receiving alerts when HH patients were admitted to outside hospitals and emergency rooms. This team has also assisted with the HH's use of the internal Health Information Exchange, and has hugely increased the amount of information that the community based providers have access to for their enrolled HH patients. Business cases were developed for each of these projects, and after each advocacy effort and subsequent success, the authors were able to build upon them for enhanced functionality.

Currently, the authors are in the process of developing systems to manage the quality of the services provided by community based organizations and internal staff, and the impact that the program is having on utilization/cost. Through a combination of a new care coordination documentation platform, data retrieved from our internal medical record and billing systems, and claims data received from the Medicaid managed care plans, quality reports and improvement protocols are being developed and implemented. The intention is to not only ensure that care coordinators within the Mount Sinai HH are providing appropriate services, but also that the interventions through the HH are in fact having an impact on hospital utilization and patients' health status. With this information, the hope is that it includes compelling evidence, and that advocacy for the program's needs are even more effective.



## NEGOTIATING THE “WIN-WIN”

Another tactic employed around growth and advocacy was to negotiate the “win-win,” by leveraging benefits of HH services to obtain assistance from various decision makers. On a practice level, the case example below represents how the partnerships with key stakeholders in and outside of the institution facilitated advocacy efforts in order to provide a patient with the services she required.

*“Marta” is a 42 year old Latina female who has severe and uncontrolled diabetes, regularly smokes K2, and resides in a Single Room Occupancy (SRO) apartment. Recently, Marta was found in her apartment, unresponsive after having smoked K2. At the time, Marta was enrolled in the HH, had a case manager at her SRO, a therapist at her outpatient mental health clinic, and attended groups at an outpatient substance abuse program. Marta had only sporadic follow-up with a primary care physician. Marta’s diabetes became life threatening when she was out of care, and was worsened by her use of K2. In response to this event, the HH social worker held a case conference with all of Marta’s primary providers, including her SRO case manager and two physicians who oversaw the outpatient mental health and substance abuse services Marta attended.*

*The case conference went extremely well, and all parties agreed that Marta required longer-term treatment for her K2 use, in a facility that could medically monitor and treat her diabetes. Unfortunately, the initial call to Marta’s Medicaid Managed Care Organization (MCO) to obtain authorization for treatment resulted in a denial. All parties involved in the case conference agreed that without proper treatment of her K2 use, Marta’s life was at risk, and her continuous hospital readmissions and ED visits would continue. Also, Marta was at risk for homelessness, as her SRO had put her on a contract due to the continuous K2 use that violated the smoking laws of the unit.*

*The HH leadership decided to leverage existing relationships with the HH contacts at Marta’s MCO, and immediately brought this case to their attention. The Mount Sinai HH team reinforced with the MCO liaison that the goal of the HH program, and the reason for the MSHH/MCO contractual relationship, was to enhance members’ overall quality of health, while reducing preventable and unnecessary hospitalizations. The MSHH team also stressed that the cost of inpatient treatment for Marta’s K2 use would be far less than continued ambulance use, emergency room visits, and inpatient hospitalizations. The MCO liaison immediately saw the severity of the situation, and the “win-win” was negotiated: proper treatment was secured for one of MSHH’s members, a treatment that was also cost-effective for the MCO.*

Numerous examples like this exist in HH work. These cases embody the spirit of the HH program: the collaboration between the providers, the MCOs, and the NYS DOH. Advocacy on behalf of members mirrors advocacy on behalf of the program as a whole. Both take place

through interpersonal relationships that were established, nurtured, and maintained from the inception of the HH. It is these relationships that enable the negotiation of the “win-win,” in this example and many others, along with having an awareness of the various players, priorities, history, and overall goals that make up the program.

## RISK-TAKING AND EMPOWERMENT

In the era of healthcare reform, service delivery within the sphere of public health is being redefined to a more collaborative and community based model of care (Lundgren & Krull, 2014). This shift in public health parallels the goals of the HH program, and reinforces the program’s significance and the implications of its success. All new changes provide opportunities for advancement, but not without risk-taking. As a State, New York took a risk by implementing such a large program, with unknown success or impact. Through the roll out of the program, NYS was one of only 19 states that decided to participate in the program, and has the second highest number of enrollees among all of the HH programs implemented (see figure below) (Center for Health Care Strategies and Mathematica Policy Research, 2015; Centers for Medicare & Medicaid Services).

Medicaid Health Home Enrollment <sup>1</sup>		
STATE	FOCUS AREA	ENROLLEES
Alabama	Broad	72,916
Idaho	Broad	8,961
Iowa	Chronic conditions	6,159
	SMI	20,900
Kansas	SMI	27,234
Maine	Chronic conditions	50,095
	SMI	2,069
Maryland	SMI & SUD	4,887
Michigan	SMI	475
Missouri	Chronic conditions	17,110
	SMI	21,248
New Jersey	SMI (adult)	--
	SED (child)	--
New York	Broad	158,460
North Carolina	Chronic conditions	559,839
Ohio	SMI	14,181
Oklahoma	SMI (adult)	4,029
	SED (child)	1,320
Rhode Island	Broad	1,995
	SMI	6,772
	SUD	2,340
South Dakota	Broad	6,138
Vermont	SUD	4,924
Washington	Broad	52,656
West Virginia	SMI	934
Wisconsin	HIV/AIDS	233
<b>Total health home enrollees</b>		<b>1,045,875</b>

SOURCE: Data as of May 2015 except for North Carolina (as of July 2013). New Jersey not yet reporting data in May 2015. See: Health Home Information Resource Center.

Broad = combination of chronic conditions and SMI and/or SUD  
Chronic conditions = chronic medical conditions only  
SMI = serious mental illness SUD = substance use disorder

Note that Oregon has withdrawn its Medicaid health home SPA and is no longer providing services under the 2703 option.



As of June 2015, 19 states have a total of 26 approved Medicaid health home models.

States with Approved Health Home SPAs (number of approved health home models)	Alabama, Idaho, Iowa (2), Kansas, Maine (2), Maryland, Michigan, Missouri (2), New Jersey (2), New York, North Carolina, Ohio, Oklahoma (2), Rhode Island (3), South Dakota, Vermont, Washington, West Virginia, Wisconsin
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Note that Oregon has withdrawn its Medicaid health home state plan amendment and is no longer providing services under a 2703 SPA.

On an institutional level, Mount Sinai and other lead HH organizations took a risk in funding a new program, a program for which success or failure did not only have implications for the institution, but also for the financial viability of its subcontracted network organizations.

On a leadership level, the authors recognized the enormous risks that accompanied this new program, and utilized them to fuel strategic decisions and advocacy efforts. In order to build a network of community based providers, to hire and employ staff whose salaries were

based largely on prediction, and to establish our HH program within our home institution and community, several risks were taken. The authors had an advantage, as both were a part of the HH landscape and roll out from the start of the program. This was true through a presence in various capacities: at hospital sites, community based organizations, different lead HHs, and different State-run workgroups and learning collaboratives. This exposure has afforded opportunities for advocacy. From the start, the authors could present the program as experts, had insight into historical implications, and could continue to discuss current and potential successes as the program further developed. Both internal Mount Sinai audiences as well as community based leadership were asked to trust the expertise of the HH leaders to develop the best program possible within State guidelines.

The most significant manner in which the authors have been able to take risks in moving the program forward has been by volunteering to take responsibility. Within State workgroups and the HH coalition, taking a leadership role on specific projects and initiatives has allowed for larger influence and development. For example, the State offered potential standards for best practices of a lead HH that were initially unrealistic. The authors took the lead in suggesting changes and improvements to the standards. The HH coalition was appreciative for the work, and was able to provide input. The State also appeared to appreciate the suggestions and soon implemented the changes. Since then, the authors have been asked to participate in and present at various other task force meetings and planning commissions.

Establishing knowledge, taking responsibility, communicating effectively, and listening actively, are all critical elements of effective advocacy and leadership. It is the authors' intent to lead by example, and for the risk-taking and advocacy efforts completed on behalf of the HH program to be passed along to the staff members that are hired. It has been extremely important for effective service provision, to hire social workers and care coordinators who are risk takers on behalf of their patients. These staff members are autonomous, confident, committed, and excellent collaborators, listeners, and communicators – they are leaders. Through strong leadership of the program, the authors hope that empowerment is absorbed by the HH staff; they then empower their patients to take risks and make positive changes in their lives. Through the staff's advocacy on behalf of their patients, they help the patients navigate through the system, effectively receive entitlements, and access resources. Of course, their efforts are not always successful or met with welcome ears. The program leaders can then step in as needed for guidance and assistance. In this way, empowerment through advocacy hits the person, program, and policy levels.

## **SUSTAINABILITY**

The nature of this program has been one in which, simultaneously, certain aspects are sustained while several others are starting anew. For example, successful systems are in place for data collection, tracking, and billing. However, in six months, the structure will change. Similarly, the HH services being provided to adults have been streamlined and best practices have been established. In January, the HH serving children and families will be established and will begin enrolling patients. Because of this structure, HH leadership has had to sustain and improve, while innovating. It has been essential to remain creative and open to new ideas and

new collaborations. Maintaining relationships, taking risks, taking responsibility, remaining mindful of the spirit/goal of the program and the patients the HH is serving, and empowering the individuals who are providing the services, allows for continued sustainability and growth.

## **SUGGESTIONS FOR SOCIAL WORK**

The profession of Social Work has a long history of demonstrating its dedication to advocacy, which compliments the initiatives and needs of the Affordable Care Act (*Allen, 2012; Golden, 2011*). Programs such as the HH have afforded social workers the unique opportunity to lead groundbreaking initiatives and to assist in current policy reform on City and State levels (*Andrews & Brown, 2015*). Although this opportunity is one to be seized by the profession, there are several lessons that have been learned through the implementation of the Mount Sinai HH program that allow the authors to offer some specific suggestions around advocacy.

The first suggestion is to build upon what *Germak & Singh (2010)* call *social entrepreneurship*. As demonstrated by the success of the various social work-led initiatives through the ACA, the profession has been given the opportunity to demonstrate its utility on a national and international scale. However, the nature of the profession and its humble roots in charitable giving, often hold social service agencies back from integrating social work practice with innovative business models that would provide further financial stability and prosperity (*Germak & Singh, 2010*). The re-design of the health care system through social work-led care coordination initiatives is an opportunity for social work services to be valued from a financial perspective. The idea of the profession embracing social entrepreneurship would require advocacy on a macro level and is one that should be explored by the profession (*Germak & Singh, 2010*). The Mount Sinai HH is assisting sub-contracted community based providers by sharing financial modeling and advocacy efforts/policy proposals to assist them in promoting and pursuing their own growth.

A second suggestion is to continue promoting a holistic approach and care coordination to social work service providers. Through the HH program's experience, social workers' ability to treat the entire person from a holistic approach has been validated. Countless times, health care professionals have thanked the HH staff for "tying up loose ends" for patients, or for always remaining available for a phone call or a visit. Social workers assist patients through the facilitation of transportation services, assisting with housing applications, connecting patients with meal delivery, scheduling specialty medical appointments, and/or helping to address behavioral health issues. The need to treat the "whole patient" has reinforced the need to hire social workers with a range of experience, who possess strong clinical skills, and who have demonstrated self-efficacy in the treatment of substance use disorders. Concurrent with *Cochran et al (2014); Lundgren & Krull (2014)*, the authors suggest that the social workers who were once trained in or focused on generalist practice, or primarily medical practice, will be encountering an increased number of patients with substance use disorders and co-occurring mental health diagnoses. Since this population can be complex and difficult to treat, it is important that social workers leaving graduate school have had some training in the treatment of substance use disorders and serious mental illness.

Finally, the authors recommend patient involvement in program planning and development. Throughout the roll out of the HH program, one area that was missing from its implementation was the involvement of the consumers for whom the program was designed. As social workers, the authors continuously advocated on behalf of the population's needs. However, the program might have been enhanced, had the consumers held a seat at the table. As Betchell & Ness (2010) argue, if programs are to be truly patient-centered, there has to be consumer involvement in its development. Social workers need to advocate for patients by not only being a voice for the patient, but also to ensuring that he/she is able to contribute along with the rest of the stakeholders.

## SUMMARY

Developing the HH at Mount Sinai has been an exciting and challenging experience. To work on a program stemming directly from the Affordable Care Act has been an honor. The authors feel especially privileged to be a part of this specific program, which aims to improve the health and well-being of the most vulnerable populations in New York City. The roll out of the program has required advocacy on the policy, program, and individual levels in order for the patient services to be successful. Although a lot has been accomplished, there is a lot more to be done. The next few years will bring new aspects of the program, including the expansion to children and families, the transition of behavioral health to managed care, and the expansive Medicaid redesign initiative, DSRIP (Delivery System Reform Incentive Payment Program). These will be tackled with the same enthusiasm, incorporating lessons learned, and always keeping the patient at the center of design and implementation.

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# **SOCIAL WORK ADVOCACY IN CANCER CARE SERVICES: THE OREGON EXAMPLE**

*Susan Hedlund, LCSW*

## **INTRODUCTION**

There are an estimated 14.5 million cancer survivors alive in the US today, and that number is expected to increase to 19 million by 2024. (*Rolland J. & Bellizzi, KM, 2008*). Previously considered an automatic death sentence, cancer is now viewed as a treatable, sometimes curable, cluster of diseases. Cancer is also regarded as a chronic illness, with greater emphasis on managing late effects and enhancing quality of life. As a consequent, the survival of cancer for millions of patients is becoming a public health issue. Side effects that include physical, psychological, social, spiritual, and financial concerns have potentially long term impacts on cancer patients and their families.

Addressing psychosocial needs of cancer survivors has become increasingly complex as treatment has shifted to the outpatient setting, patients are afforded more treatment options, and families are bearing increasing responsibility for managing care. The IOM Report, *Cancer Care for the Whole Person, (2008)* noted that counseling, support, education and health promotion is needed but often not provided to cancer survivors. Another IOM Report, *From cancer patient to cancer survivor: Lost in transition, (2006)* observed that patients often felt abandoned at the end of treatment. Based largely on these reports, the American College of Surgeons Commission on Cancer initiated new standards for all accredited cancer programs that have a profound affect on psychosocial services (*ACOS, 2014*). By 2015, all accredited cancer centers must implement three components of psychosocial care: *patient navigation*, which attempts to eliminate barriers to access to treatment; *distress screening* for all newly diagnosed patients being treated at the cancer center, and *survivorship care planning*.

The increasing number of cancer survivors and complex associated psychosocial issues as well as the new accreditation standards provides the prospect of pivotal roles for social work. In particular, social workers as the psychosocial experts on the oncology team represent significant resources in developing programs and services for patients and families, while also providing operational leadership within the cancer centers. This chapter discusses the advocacy initiative of social work in creating a new patient care process for early identification and intervention with cancer patients.

## **OREGON PROGRAM DEVELOPMENT**

Oregon Health and Sciences University is a one of the largest health systems on the West Coast and features a rapidly expanding cancer program component. Within that system, oncology social work was invited to actively assist the system in meeting the new standards and creating an enhanced program of support for cancer patients and families during and after treatment. The procedural steps have involved a community needs assessment addressing actual and potential barriers to care, identification of an appropriate screening tool to identify patients at risk for greater distress, and implementation of a system for follow up and intervene. Additionally, work was needed to integrate the new patient care interventions into the electronic medical record. Finally, a comprehensive program of

support during and after treatment needed to be developed. The following describes each component of the program development process.

### ***The Community Needs Assessment***

In the initial stages of program development, the Oncology Patient and Family Support Services manager (a social worker) collaborated with the cancer center outreach director, the tumor registrar, and the Oregon State Partnership for Cancer Control (SPCC) to assess the needs and identify barriers to cancer services. SPCC is responsible for tracking prevalence, surveillance, and prevention of cancer across the state. Not surprisingly, people of color (including African-Americans, Asian, Latino and Native Americans) experience later diagnosis and greater mortality than their Caucasian counterparts. Overall, Oregon does not have significant numbers of ethnic minority residents and the university-based cancer center was sufficiently addressing the needs of these population sub-groups. The state however is largely rural and for those individuals with more rare forms of cancer, coming in the metropolitan Portland area for medical often proves burdensome. Recognizing this patient experience, the OHSU cancer center engaged in statewide outreach that includes providing community grants to smaller cancer programs statewide to enhance access. Emergency grants are additionally available through the Department of Patient and Family Support Services for patients in need who travel from outlying areas. Further, the health system is engaged in developing patient and family housing with social work assuming an active role in these efforts.

### ***Distress Screening***

Social work has always been involved with identifying and addressing the distress of clients/patients regardless of setting. Numerous studies (*Weisman, 1976; Christ, 1991; Holland, 1991; Zabora et al, 1997*) and the IOM (*2008; 2006*) estimate that approximately 30% of people with cancer experience significant “distress”. The term “distress” has evolved in use as less stigmatizing than the terms “anxiety” or “depression”. While a certain amount of distress is considered “normal” after a cancer diagnosis, distress can impede adherence to treatment, impact relationships, and most certainly impact quality of life.

The recent College of Surgeons’ mandate to screen all newly diagnosed cancer patients for distress has presented both challenges and opportunities for oncology social work. In response to the mandate, OHSU initially considered use of the National Comprehensive Cancer Network (NCCN) Distress Thermometer (*NCCN, 2014*). The Distress Thermometer is completed by patients; the left side of the tool portraying a thermometer on which the patient self-reports the level of distress that they are experiencing, while the right side of the tool offers twenty boxes that the patient can check indicating distress across physical, psychological, social, and spiritual domains. NCCN suggests follow up for anything checked above 5 on a 1-10 Lickert scale.

After piloting the Distress Thermometer for thirty days, OHSU staff identified two important operational issues - completing it “on paper” added significantly to work flow and concern arose that patient responses to the tool were inconsistent, leading staff to question whether patients were confused about the word “distress” or the thermometer analogy or more fundamentally did not want to acknowledge the extent of their distress.

Given these issues, the University of Texas Cancer Center was contacted about their experience in using the Edmonton Symptom Inventory (ESI). With their permission to use the ESI, we then



partnered with the OHSU directors of Rehabilitation and Nutrition Services in exploring the benefits of a “Prehab” approach for cancer patients (*Silver & Baima, 2013*). This approach suggests patients receiving earlier, proactive assessment and intervention across multiple domains remained healthier and lost “less ground” during treatment. Two questions were added to the ESI regarding nutritional status and two regarding rehabilitation issues.

## **IMPLEMENTATION ISSUES**

With the instrument identified, we next attempted to implement the screening electronically with an interface to our Electronic Medical Record (EMR). This proved to be a significant challenge, requiring regular consultations with the health system’s IT department. As there were no systems in use that imported patient questionnaires into the EMR, there was considerable interest in pursuing such a merger. “*MyChart*”, an email based interface for patients and their health care providers, was chosen as the vehicle for conveying the Distress Screen data. Approximately 50% of OHSU oncology patients had signed up for *MyChart* and consequently we needed to develop a system to reach to those patients not yet enrolled. Touch screen tablets were ordered for patients to complete the questionnaires as they checked in for clinic appointments. Unfortunately, the tablets proved to be problematic. Numerous “false answers” were registered and computer use was challenging for some patients. As it was also necessary to sanitize and recharge the tablets between use, tablet availability was an intermittent issue. IT worked with cancer center staff in identifying and resolving these issues.

Social work staff created an algorithm to address concerns that register a 7 or higher on the psychosocial questions. These include initiating an indepth assessment for depression and/or anxiety. For patients checking a 7 or higher on depression, the social workers administer a Patient Health Questionnaire (PHQ-9), complete a psychosocial assessment and create a plan of intervention. For patients indicating 7 or above on anxiety questions, the social worker administers a Hospital Anxiety and Depression Scale (HADS), completes an assessment and an intervention plan. Questions related to nutrition or rehabilitation needs scoring “7” or higher are automatically routed to the Nurse Coordinators for followup. The social workers meet frequently with the other involved disciplines (MD’s, RN’s, RN Coordinators, admitting staff) to educate them about the mandate, need and process. While staff have been supportive, it has taken repeated efforts to ensure buy-in of all staff.

### ***Barriers and Lessons Learned***

One important aspect of our experience was to ensure that distress screening was regarded as a function of the entire interdisciplinary team given that distress, nutritional and rehabilitation concerns impact all patients’ quality of life. While social work has assumed responsibility for the development and implementation of the process, it has been important to share the responsibility of further assessment and intervention across multiple disciplines.

Another important takeaway is that “screening” is not the same as an assessment. Screening may help to identify patients in need earlier, but further assessment and intervention may still be necessary. Our barriers have included initial staff resistance and reluctance as well as the challenges with IT development. We have had to rediscover our enthusiasm for the project more than once, but are convinced that patients will gain from earlier, more proactive staff involvement. We are pleased

with having made a major contribution to the health system by creating new patient care systems that utilize surveys through *MyChart*.

### ***Survivorship***

The growing number of cancer survivors and associated physical and psychosocial health needs for this population underscore the importance of maintaining a “population health” perspective. Cancer survivors have distinct and unique needs. The time following primary treatment for cancer is now viewed as a distinct phase in the cancer continuum. It occurs when individuals make a transition from “patient” to “survivor” (*Miller, et al, 2008; Rowland, 2008*). When active treatment ends, the post-treatment phase begins and may be characterized by unexpected anxiety, generalized fear, and management of late and long-term effects resulting from treatment (*Ganz, 2006; Rowland & Bellizzi, 2008*). Survivors often experience long-term consequences of cancer and these after-effects often negatively impact on quality of life and patients’ physical, cognitive, social, and emotional functioning (*Rowland & Bellizzi, 2008*). Rowland (*2008*) notes that the post-treatment experience involves a series of adjustments occurring in three primary domains of quality of life: physical, practical (financial), emotional, as well as the search for meaning in the experience.

The College of Surgeons requires that all patients completing treatment for cancer be given a treatment summary and care plan at the end of treatment. The summary includes the type and stage of disease and all conferred treatments; the care plan provides recommendations for surveillance and health behaviors going forward. In our instance, this contributed to a number of challenges. First, the electronic medical record did not “auto-populate” this document, thus requiring hand-entered data which proved both time consuming and non-reimbursable. The survivorship summary is reviewed with the patient and while the physician and Nurse Practitioner can be reimbursed for this interaction, provisions for social work reimbursement do not currently exist.

## **SUMMARY**

Recognizing that cancer survivors need and want programs of care to help them adjust to their post-treatment lives, under the umbrella of Patient & Family Support Services, wellness programs have been expanded to include acupuncture, massage, mindfulness-based stress reduction, writing workshops, and yoga. Within this context, social work has spearheaded a survivorship task force including oncology providers, researchers, and patients that make recommendations to the institution going forward. One important component of program development and advocacy has been the initiation of screening around psychosocial concerns of patients and families.

As is true with any unfunded mandates such as the ones required by the College of Surgeons for accredited cancer programs by 2015, there is frequently resistance to change. The three new standards in the psychosocial domain however have also provided rich opportunities for social work to provide leadership and contribute to program development. It also afforded the opportunity to enhance teamwork - benefitted by social work’s historic focus and skill in collaboration.

The remaining steps in the OHSU process include completion of the distress screen rollout and continued implementation of survivorship programs. These efforts involve much work, additional involvement and engagement by social work, the clinical team, and administrators. The opportunity is

great, however, and the time is ideal for social workers to assist cancer centers in implementing such initiatives. It is of critical importance that in our setting social work is “at the table” more than ever before and that our voices and that of our patients are being clearly appreciated.

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# **BREAKING DOWN BARRIERS: CARE COORDINATION INTEGRATION WITH AN EMERGENCY DEPARTMENT “SUPER-UTILIZER” POPULATION**

*Karen Fattore, LSW, ACSW, MBA and Nicole Vega, LSW*

## **INTRODUCTION**

Significant effort has been focused in recent years on treating the “whole person” in order to achieve enhanced patient health outcomes across the spectrum of health care delivery settings. This requires looking at the whole person in their environment in order to determine based on Maslow’s hierarchy of needs what any one individual is lacking in order to achieve a higher level of health and happiness. This is often referred to as *Population Health Management (PHM)* or the organization and management of how healthcare systems are perceived and services delivered to patients in an individualized manner. Social workers are well aware that no two patients are the same and will not respond in the same manner to provider interventions.

PHM is utilized in an effort to make health care more clinically effective, more cost effective and to bring about positive outcomes for all involved in the process. PHM means the proactive application of strategies and interventions to defined groups of individuals across the continuum of care in an effort to improve the health of that group at the lowest necessary cost (See: <https://www.healthcatalyst.com/population-health/>). PHM has meshed within it a “person in the environment” focus which is central to the practice of social work. Attention to an integrated delivery model which formulates connections between medical professionals from the hospital with community providers earlier in the disease process activates an improved holistic approach. It was this perspective that contributed to the creation of *Project Connect*. Extending the care delivery process through patient interactions outside of the hospital was initiated with the intent of affording a customized approach for our most needy and most frequent health service utilizers. It reflected advocacy for both the patient population and the health system.

## **SERVICE NEEDS: THE CATALYST FOR CHANGE**

The Reading Health System is located in West Reading, Pennsylvania and serves individuals from throughout Berks County, an area that includes many individuals from the city of Reading. In 2010, Reading had been listed as number one of the poorest communities in the United States (*Tavernise, 2011*). At the same time, the Reading Hospital Emergency Department is the busiest single site hospital ED in the state of Pennsylvania, averaging 350 to 400 visits per day. Higher rates of poverty are usually also associated with lower levels of education (*Tavernise, 2011*). Lower levels of education contribute to lower pay rates and minimal access to the health care system. Lower education may also impede patients’ ability to understand the complexities of the health care system and their ability to appropriately utilize the system without outside assistance and support. In the instance of the Reading Health System, hospital social workers were frequently consulted to assist ED patients with resources, education and social/emotional issues. This correlated with Care Management Department observations that patients in the community often sought medical treatment in the Emergency Department without

necessarily having medical emergencies. Nationally ED visits for patients with a primary mental health or substance abuse diagnosis are increasing, with increased visits by 75% from 1992-2003 (*Bazelon, 2015*). The Care Management Department regarded this circumstance as a driving force to proactively develop a proposal focused on both lowering unnecessary emergency room visits and educating the community about health care use. The proposal was developed to test a service hypothesis: “If the care management department specifically designated an outpatient social worker to assist patients in coordinating services, accessing community resources and maneuvering the health care system, could the hospital lower unnecessary Emergency Department utilization and thereby lessen the costs of care within the system’s continuum?”

To pursue this question, research was initiated on “super-utilizers” of other health systems. At the inception of the project in 2010 there were very few hospitals that employed an outreach social worker to case manage super-utilizer populations. As part of the research, contact was established with the Camden (New Jersey) Coalition of Health Care - an established program involving three New Jersey hospital systems. Their support and shared startup experiences proved beneficial in formulating our goals and objectives. The Community Needs Assessment conducted in January 2013 by The Research and Evaluation Group, Public Health Management Group, Philadelphia, PA was examined and an additional inquiry was made to members of the Society for Social Work Leadership in Healthcare to determine if any similar initiatives were underway. While a few hospitals replied, their examples were primarily focused on ED social workers assuming coordination roles as part of the ED workflow.

In our instance, daily ED social work volume could not effectively be the operational arm for this initiative. While as social workers we knew the hot spots in our area, the more significant need was to work with the patient in their own environment. During our program design phase, we sought a means to blend meeting community needs for this population while assisting our health system in lowering unnecessary emergency room visits. The consensus was this could be best accomplished by providing a dedicated mobile outpatient social worker. Our information technology department was requested to make a database query into the frequency of patients registering in the ED ten or more times during a three month period. The number of these instances was greater than anticipated, and in order to prioritize those with the most immediate need, it was decided to focus on the top 50 super-utilizers. While sought, an analysis of ED expenditures for the frequent service utilizer was difficult to quantify.

The Care Management department social workers wanted the intensity of their inpatient work to be expanded into the community for patients identified at “high risk” for readmission. As the Centers for Medicare and Medicaid (CMS) began to focus on the potential of readmission penalties, the health system recognized that work within the care continuum needed augmentation. Over the course of the implementation it became evident that social and economic forces in combination with biological factors were significant factors affecting the population and its health care service use.

## **TARGET POPULATION**

In the initial stages of program development, the steering committee identified admission criteria for patients who would be followed by the outpatient social worker. The first thought was to follow patients who visited the Emergency Department at least ten times during the preceding six months. This was similar to the focus of the Camden Coalition of HealthCare providers and the success of that program was viewed as one benchmark throughout our planning. The Coalition reiterated that in order to lower emergency room visits, it was first crucial to assist patients in obtaining those community resources to keep them housed, clothed and with basic necessities before chronic disease care management interventions could be introduced. During the first two years of implementation the Care Management Department determined that returning inpatients had benefitted from outpatient social worker support and community linkages. As a consequence the program started examining a wider net - patients who were super utilizers of the emergency room and as well as patients who were readmitted after recent discharge. The target population was ultimately defined by the following criteria: 1) three or more readmissions in the previous quarter, and/or; 2) ten or more emergency room visits in the last six months, and/or; 3) at least one or more chronic medical condition along with a social/psychological/cognitive problem affecting their ability to access community based care that did not necessitate an emergency visit and/or; 4) patients misusing existing resources and underutilizing care because of barriers to navigating the healthcare system (*Project Connect Steering Committee, 2010*).

As a voluntary initiative, The Project Connect Program was established by The Reading Hospital and Medical Center to provide services to patients and their affiliates. Services are provided in the comfort of patients' homes and in the community. Participation is free and patients have the option of discontinuing services at any time. If a patient chooses not to participate, the outpatient social worker will shift focus to the next person on the waiting list. Having patients sign a service agreement to participate assists in securing patient buy-in toward collaboratively working with the outpatient social worker and initiating changes in their lives. When possible, patients are visited in the ED or the hospital to start the engagement process.

## **PROGRAM INITIATION**

In the initial months of program development the Care Management team noted what medical social workers have long recognized - the impact of social determinants on patient health outcomes and the negative implications if there is little connection to follow-up care. The intent was to install an outpatient social worker focusing on social/emotional barriers that prevented patients from improving their medical outcomes. There was consensus that the health system's expensive diagnostics, interventions and labor would not produce optimal outcomes without concurrently addressing the unique needs of vulnerable populations. The program now known as Project Connect would serve as the outpatient connection to the inpatient Care Management Department. By focusing on population health the program would capture administrative attention, promote patients' access of the right care level, reduce ED care costs and enhance patient outcomes for this segment of the population.

The Project Connect program start-up occurred in phases and was no small endeavor. Research focused on the variables associated with potentially avoidable emergency use. Discussions were held with our chief of emergency room physicians and emergency room nurse directors to determine what type of patients contributed to overcrowding and long wait times. Time of day and day of week utilization patterns were identified. There was a wide range of diagnoses but there was limited available data regarding avoidable use. The ED collaboration was intended to confirm that our thinking was more than a perception.

The request to fill a fulltime position to serve in the role of mobile field social worker at that time did not come easily. A grant request was written but the hospital administration did not initially approve it. The request for a full time outpatient social worker was resubmitted for three consecutive years. While it gained some attention, it was not approved until the third year. It was not until the biopsychosocial aspects of healthcare delivery and implication for patient self-management became more evident to administration that approval was ultimately granted. Factors outside of medical care such as race, education, housing and income are important in determining how healthy or sick we are. Social determinants of health are the circumstances in which people are born and reside; they can include one's neighborhood, economic stability, education, social and community context and health and health care (*Knickman, 2013*). It becomes crucial to understand the relationship between how population groups experience their environment and how each environment impacts health. These impacts affect both behavioral and physical health as well as the manner of health care use.

## **FACTORS IMPACTING PROGRAM DEVELOPMENT/OPERATION**

A focus group of human services agencies was formed to gather information, facts and perceptions about the needs of the patients who would frequent the ED for non-emergency services. It is noted that some agencies had overlapping patients and that joint planning and coordination did not occur routinely. Fragmentation of care was a significant concern and provided an opportunity for interagency collaboration.

A Project Connect Advisory Committee was formulated to engage stakeholders in the development of program goals and measurements. The committee included: the system vice president responsible for care management, outpatient services and ambulatory care; the Emergency Department Chief; a psychiatrist; an ED social worker and case manager, and; family medicine faculty, clinic administrator and clinic physician director. The community shelter director, case worker and a Department of Public Welfare administrator were also initially included. Discussion was held with our legal department regarding the safety and risk needs that might be present for a community based social worker. An outcome of those discussions was that a safety training course conducted by the health system security department was required for our social worker.

The program costs for reducing inappropriate ED use were carefully analyzed. Fiscal services personnel provided their analysis but had difficulty at first in determining the correct variables to take into account. It can be very difficult to quantify the "potential costs" of a patient once they have been able to organize themselves and not utilize the emergency room or

prompt hospitalization. At this point the system is primarily looking at the decrease in visits while continuing to determine the best business method to show results. Verbal self-reports from patients who noticed the impacts the program has had on their own lives are plentiful, but more statistical data is needed to concretely document these impacts on the system.

During the last four years of program operation we have observed consistent themes that represent the greatest challenges for our patients with regard to quality of care. Barriers develop when patients have poor relationships with their primary care physicians and are unable to appropriately express their medical concerns and needs. Some patients can be “non-compliant” and prompt future problems when specialists chose not to see them due to frequent missed appointments. Some patients have lost their therapist and/or psychiatrist in these circumstances despite having valid reasons for their non-compliance such as lack of transportation or funds to pay for public transportation, homelessness, or previously untreated mental health problems that affect their ability to appear for appointments. It becomes crucial for the outpatient social worker to assess the patient in their environment, determine what barriers exist to appropriately using care and then work with the patient to help them maintain their physical health as well as social and emotional stability.

A high percentage of patients in Project Connect manifest chronic medical conditions with behavioral health disorders and/or coexisting addiction problems. Data collected from FY 2011 through 2014 reveals that 97% of Project Connect patients have a diagnosed mental health disorder, while 60% of patients give evidence of an addiction problem. Navigating the complex health care system while suffering from addiction or an untreated mental health disorder can be very difficult for these patients and they usually have few social supports. The outpatient social worker has been a valuable resource to these patients in obtaining the necessary mental health or addiction programs and supporting them on the road to recovery.

## **OUTREACH EFFORTS**

A mobile “feet to the street” community approach is what makes this outpatient social work position a specialized role. The skills to deliver outpatient care management services for a designated high-risk medically and psychosocially complex population cannot be overstated. The outpatient social worker not only has to develop therapeutic relationships with the patients, but promote community relationships with other entities such as medical practices, mental health agencies, department of public welfare and Social Security office.

Work locations for this specialist vary between the health system, home and community. The social worker goes to where health happens; this may be in common places such as residences, a shelter, tent city or park bench. Patients tend to be from vulnerable populations in the community with the majority living in the city proper. The population “hot spots” within the city fluctuate to the extent that patients are transient. Additional analysis is anticipated regarding where Berks County super-utilizer subpopulations reside, work and spend their time so as to determine if more geographically targeted interventions can make an impact.



A strong professional relationship exists with Berks Community Health Center which is a federally qualified clinic in the City of Reading. The clinic staffs are a valuable asset in expediting appointments and collaborating on challenging high ED utilizer cases. Community engagement and partnerships with other businesses/associations have occurred with donated goods provided on a case to case basis from entities such as the Berks Greater Food Bank, City Thrift Shop, Integra Business Solutions, the Rudden Family Foundation, Wheels for Change, Re-style Boutique-work wear, Immanuel UCC Outreach and Lions Clubs.

The outpatient social worker has also cultivated strong linkages with local emergency medical responders. The social worker meets quarterly with EMS and fire department personnel to strategize on lowering the frequency with which the emergency room is utilized for non-emergent reasons. EMS teams have proven to be a significant referral source for potential new patients with Project Connect. The outpatient social worker also is able to engage the EMS teams in overcoming some patients' initial resistance to coming to the hospital for necessary medical attention.

It is important to note that the outpatient social worker is not a substitute for nor replace telephonic case management navigators or home health care visits. The outpatient social worker has significant face-to-face contact in developing a therapeutic relationship and facilitating the collaboration needed to execute plans across the care continuum. The social worker strategically focuses on issues with which patients are willing to work, addresses any ambivalence and follows on a longer term basis presuming the patient is willing. Much is gained by visiting high risk of return patients in their home setting. Typically, patients have one or more chronic illnesses which are poorly controlled. In many cases a behavioral health or substance use disorder coupled with social barriers prevents utilization of care in the appropriate setting. The historic default in these instances has either been an ED visit or simply not seeking prompt treatment. This behavior often leads to an otherwise preventable admission or readmission. The impact of culture is noted as a strong factor in how patients view and maintain their healthcare conditions. Project Connect patients have diverse backgrounds, with 80% identified as Latino.

Project Connect has been actively engaging super-utilizers since 2011 and has contributed to successful outcomes for both the patients and health system. Significantly, in the initial startup year, the program was able to reduce emergency room visits by 62% and inpatient stays at 82%. In 2012 there was a 56% reduction in emergency room visits and a 48% decrease in admissions; in 2013 those numbers were 55% and 36% respectively, while in 2014 the total reduction in emergency room visits was **21%** and a decrease in admissions of **37%**.

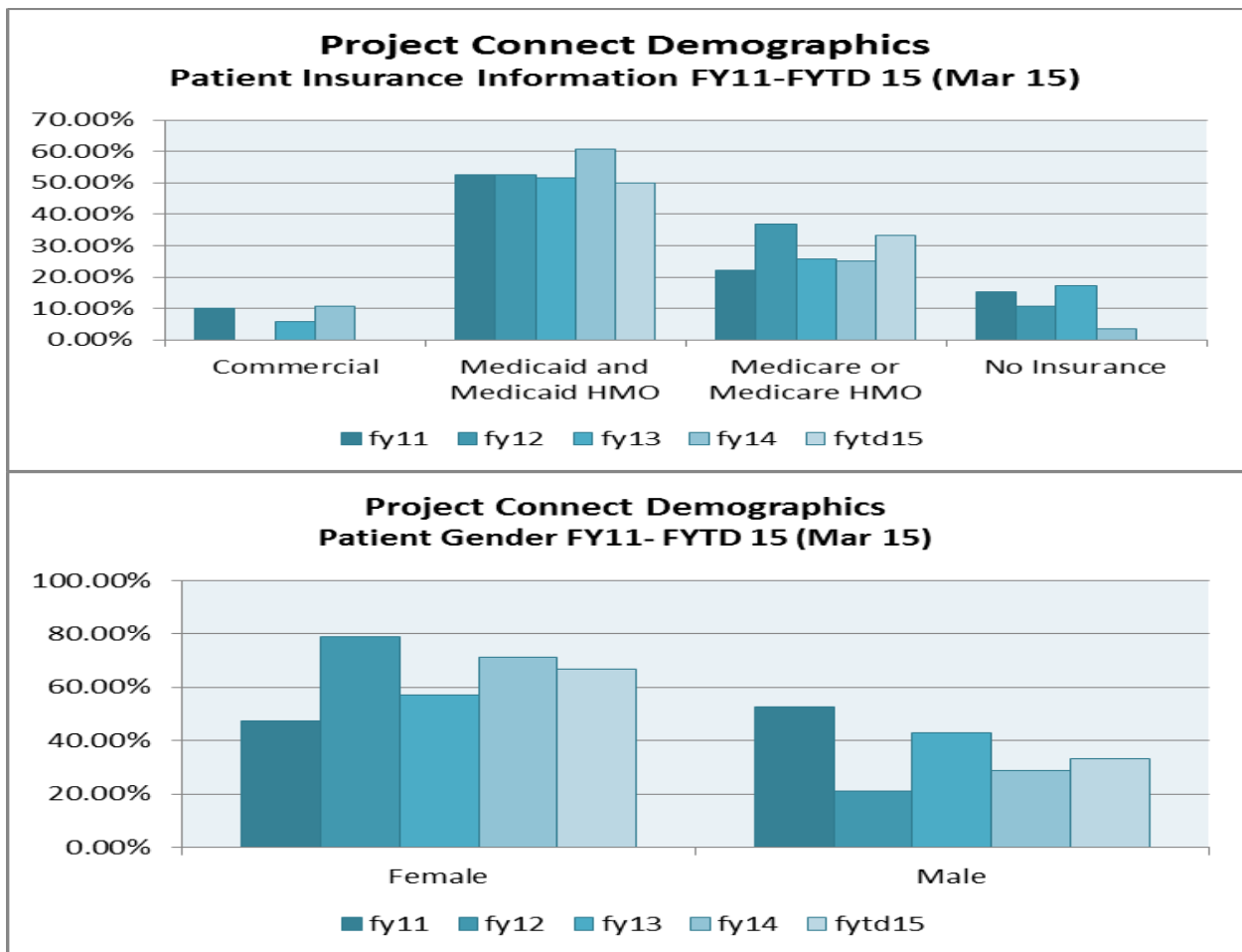
One particularly unique effort of Project Connect is the collaboration that has evolved with the family medicine practice. Through this relationship the outreach social worker has been able to take a third year medical resident out once a week to have vitals taken and conduct medical education in patients' homes and in the community. During one home visit with a diabetic patient, the physician was able to provide diabetic education to all the other adults living in the household, something which had never happened because they do not attend office visits with the patient. This proved very helpful several weeks later as the patient experienced an extremely low blood sugar level and her daughter, remembering what the doctor had taught her,

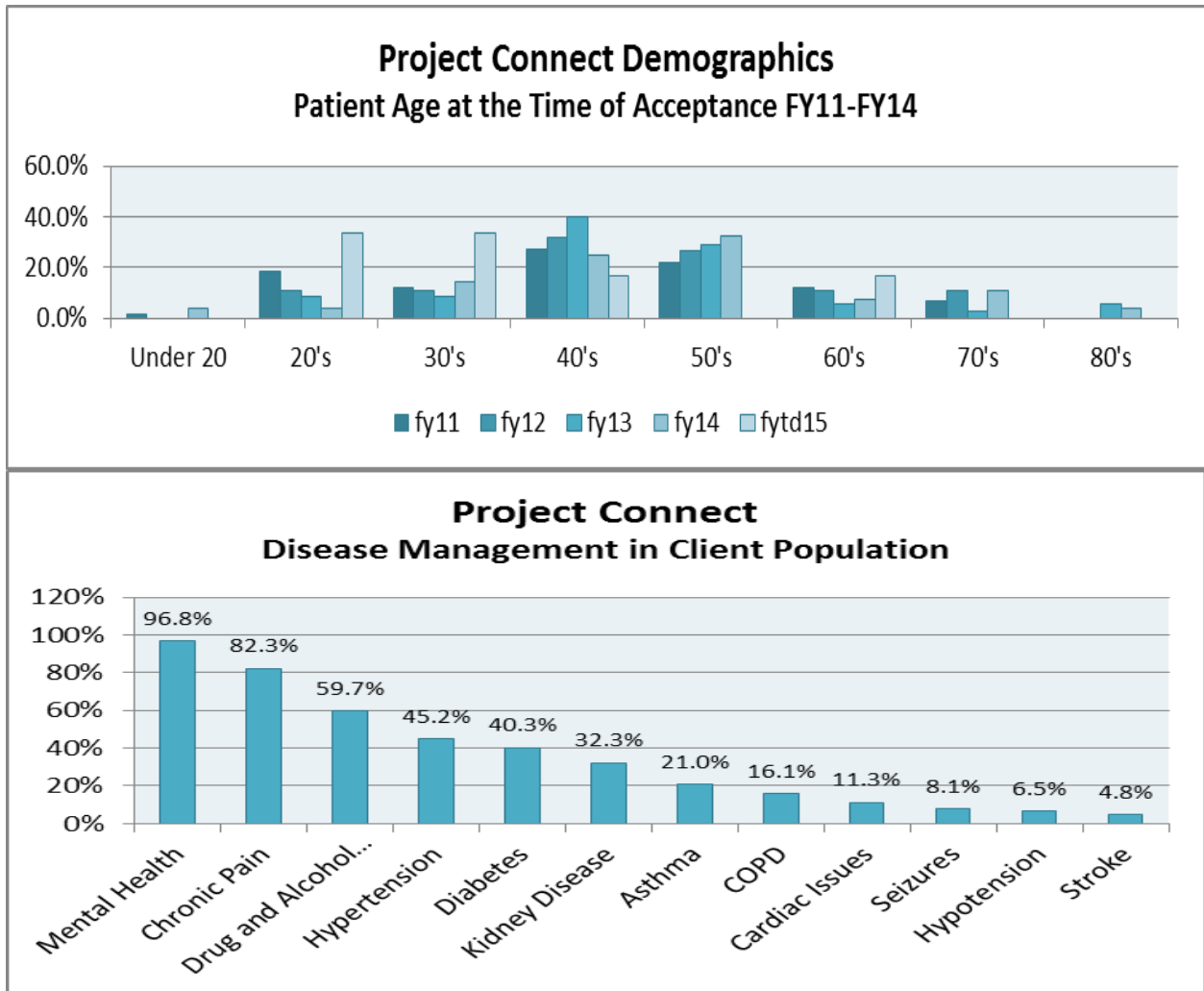
was able to utilize the glucagon pen and call 911 immediately. The family became comfortable with supporting their diabetic mother and also working on developing healthy eating habits.

The outpatient social worker is able to meet patients in a variety of environments – a factor important in seeking to make the patient most comfortable. Patients are assisted in becoming their own medical advocate and champion for the future. Reflecting Maslow’s (1943) hierarchy of needs, Project Connect contributes to patients fulfilling their most basic needs (e.g.: shelter, food, etc.) and then moving on to address more complex needs such as health.

## PROGRAM PERFORMANCE STATISTICS

The following data reflects the historic and present performance of Project Connect. The majority of patients utilizing this program are female Medicare or Medicaid recipients aged between their 30’s and 50’s. As noted previously, nearly 97% manifested some form of behavioral health issue and high percentages were noted of chronic conditions.





## FUTURE OUTREACH EFFORTS

As we look at the future of Project Connect and how the outreach program supports both the Reading Health System and the community at large, our desire would be to expand the impact of the program through involvement of another full time outpatient social worker. This desire is based on the level of patient referrals from a wide range of sources and the prospect that the waiting list for the program will expand. As we continue to redefine and enhance data collection, it will be important to continue to determine the optimal way of impacting on those patients with the greatest needs. Accurate, timely and comprehensive data will continue to be the foundation of program evaluation and planning.

Going forward, the outreach program would be further enhanced by increasing the amount of dedicated time available with the third year family practice residents. This service has proven to facilitate patient trust in the medical system and affords a unique opportunity for new medical professionals to cultivate a better understanding of the patients' own environments. Both patients and the residents have indicated that this has been a positive relationship.

For other health care systems, it is important to underscore the value of conducting a comprehensive community needs assessment. Once you have a better understanding of the resources, community partners and patients' concerns, you can more accurately focus the intent and structure of your own outpatient program. Applying concepts from person-in-environment domains of social work practice and everyday social work methods provides an important framework in a systems approach to care for high healthcare utilizers.

## SUMMARY

Overall, the Reading Health System has experienced success with Project Connect. While it has been difficult to precisely quantify the results in monetary savings, we have seen significant declines in emergency room visits and inpatient stays. We also have qualitative data, from patients who have their own story to tell on how the support of the outpatient social worker assisted them in getting healthier and back on track in their own lives. Provisions of the Patient Protection and Affordable Care Act emphasize earlier interventions to keep people healthier longer. Our high utilizer population has benefited from the customized approach of the Project Connect initiative. The health system has gained enhanced insight on ways to improve the quality of care to the neediest of patients in the high super utilizer population.

Project staff continues to work on optimizing how to collect relevant data, track and trend diagnoses, and summarize the medical needs of project patients. Further tracking of appointments, barriers that interfere with accessibility, and delays in availability for prompt outpatient care are project priorities. Teaching patients to better self-manage their conditions and clearly communicate with their providers in ways they can understand and apply also remains an ongoing priority. We know that medical care outcomes and cost can be measured; what needs further emphasis is recognizing the impact of social determinates on patient health and service outcomes. It is extremely important to constantly have a "check in" with the community and the patients that being served so as to evaluate any changes in the community and how best to support those with the most significant social, emotional and physical needs.

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# **ADVOCACY EFFORTS TO ADDRESS THE SEXUAL HEALTH AND INTIMACY NEEDS OF AN ACTIVE DUTY MILITARY POPULATION**

*Ihsan Rogers, MSW, LCSW-C*

## **INTRODUCTION**

This chapter presents the issue of sexual health and intimacy needs in the military, including the unique factors influencing these needs, the scope of the issue and implications. It discusses the programmatic interventions initiated to address these needs. The role of social work in this process is underscored, particularly the nature of advocacy as a social work practice function.

Sexual health is a state of physical, emotional, mental, and social well-being related to sexuality. It involves being intimate with a partner and effectively communicating sexual needs and desires. In a battle-injured population, service members often experience sexual disability, considered one of several "invisible" injuries, associated with multiple combat injuries including dismounted complex blast injury (DCBI), traumatic brain injury (TBI), post-traumatic stress disorder (PTSD) and spinal cord injury (SCI) (*Tepper, 2014*). In the face of substantial physical loss, healthy intimate relationships and secure emotional attachments add meaning to life, support resiliency and contribute to successful recovery from physical and mental trauma. Conversely, lack of healthy intimacy can significantly impair recovery and contribute to ongoing mental health problems and suicide (*Ritchie, 2003*). Addressing sexual health in a battle-injured population, systematically and comprehensively, has the potential to improve self-perceptions, overall health of relationships, resilience and mission readiness.

## **THE IMPACTS OF PTSD AND TBI**

United States combat veterans of Operation Iraqi Freedom and Operation Enduring (OIF/OEF) are at high risk of developing both PTSD and TBI (*Schnurr & Gradus, 2010, as cited by Cameron et al, 2011*). The effects of PTSD and TBI on sexuality among returning veterans have yet to receive adequate research or clinical attention (*Cameron et al, 2011*). Post-Traumatic Stress Disorder (PTSD) is the most prevalent mental health diagnosis among veterans enrolled in healthcare at the Department of Veterans Affairs. The negative impact of PTSD on physical and emotional health and interpersonal and occupational functioning has been well documented. Thus it is not surprising that Veterans with PTSD experience increased rates of sexual dysfunction (*Tran, Dunckel, Teng, 2015*). Sexual functioning problems have been linked to both physical and psychological injuries but have received little attention – likely due to low reporting, which reduces the estimated burden and perceived importance (*Wilcox, et al 2014*). PTSD can be a significant obstacle to sexual quality of life, with a recent study of OEF/OIF male veterans with PTSD showing that 30.5% of the sample also screened positive for sexual problems (*Nunnink, Goldwater, Afari, Nievergelt & Baker, 2010*). Similarly, TBI has been linked to sexual difficulties including hyposexuality, hypersexuality, changes in the sexual response cycle, worsened body image, and decreased emotional well-being (*Oddy, 2001*).

Cameron et al (2011) note that treatment focusing on improving PTSD symptom coping, decreasing anger and hostility, addressing sexuality concerns, and fostering emotional trust and intimacy can lead to greater relationship satisfaction for veterans and their partners. Sexual intimacy is an important target for recovery. Intimate relationships and sexuality provide affective and physiological soothing, an opportunity to repair attachment capacity, and a venue for achieving balance between cognition and affect (McFarlane & Bookless, 2001 as cited in Cameron et al, 2011).

TBI can affect sexual functioning through changes in neuroendocrinology, other physical alternations (e.g. pain, fatigue, blast-related wounds), and relationship stress caused by role reversal, behavioral changes, decreased sense of self-esteem and masculinity, and increased psychological distress. Thus, the high prevalence of TBI among OEF/OIF/OND veterans frequently occurring in conjunction with PTSD and other mental and/or physical health disabilities places these veterans at significant risk for sexual difficulties and undermines their overall quality of life (Cameron et al, 2011). More than 60% of people with TBI exhibit some challenges with sexual functioning, including dysfunction of the sexual response system, sexual expression, and sexual relationships; the likelihood of these challenges increases with the severity of the injury (Aloni & Katz, 2003 as cited by Cameron et al, 2011). The most common sexual changes after TBI include lower sex drive and difficulties with arousal (i.e. erectile functioning, vaginal lubrication) and orgasm (Cameron et al, 2011). Many veterans with mental health diagnoses are prescribed a number of psychotropic medications that can assist with anxiety, impulsivity, anger, and low mood (Mohamed & Rosenheck, 2008, as cited by Cameron et al, 2011). Many antidepressant medications, particularly selective serotonin reuptake inhibitors (SSRI's), are also associated with sexual side effects as varied as low libido, ED, anorgasmia, and what is referred to as "pleasureless orgasm" (Csoka, Bahrnick, & Mehtanon, 2008, as cited by Cameron et al, 2011).

Unfortunately, sexual functioning problems like many of the invisible wounds of war are stigmatizing, which in turn often limits treatment seeking (Wilcox, et al 2014). It is important to recognize the unique sexuality needs of single veterans, whether that might be support in seeking relationships or identifying strategies for individual sexual expression (Cameron et al, 2011). Clinicians seeking to address concerns about sexual functioning need to consider several important issues to maximize their clients' ability to benefit from interventions. These include attending to the context of treatment (i.e. ensuring privacy and a nonthreatening environment by focusing on trust and rapport-building); the role of cultural and diversity factors in the clients' experience of military service, disability, and sexuality; and the clinician's own personal beliefs regarding sexuality and disability. Clinicians must consider the importance of adopting a therapeutic stance that is disability affirmative and sex positive, and integrating these standpoints with assessment and the available empirically supported treatment options. Clinicians may be hesitant to attempt interventions addressing sexual expression if they have not had specific training in sex therapy. For some veterans, referral to a sex therapist or another mental health professional with training in sexuality may be indicated (Cameron et al, 2011)

Of primary importance in conducting a sexual health assessment with returning veterans is the ability to establish sufficient rapport to allow for discussion of sexual health and sexual dysfunction (Bellfield, 2007 as cited by Cameron et al, 2011). It is essential to assess a range of

life domains that are relevant to sexual well-being, including post deployment transition issues, mental health problems, physical disabilities, and the veteran's cultural background. In addition, it is essential that veterans receive a medical evaluation to evaluate the role of any physical or medication-related factors that may play a role in sexual well-being (*Cameron et al, 2011*). Treatment of sexual concerns can be integrated with treatment of PTSD and/or TBI. By working to normalize sexual concerns and to become knowledgeable about sex-related interventions, clinicians can play an important role in maximizing an improved overall quality of life for OIF/OEF/OND veterans (*Cameron et al, 2011*).

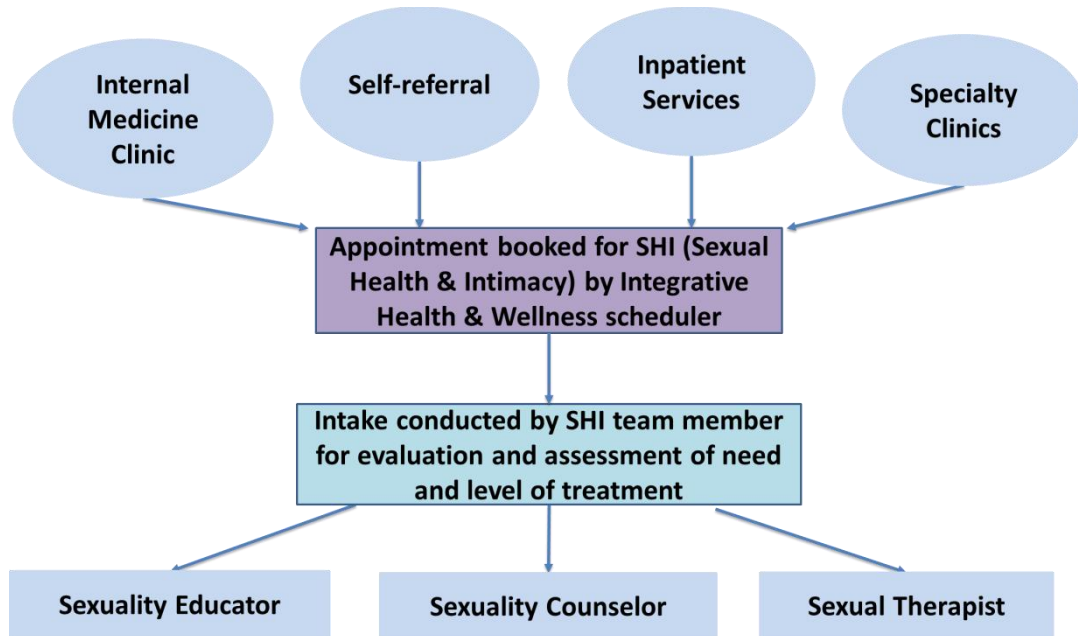
## **BACKGROUND**

The National Intrepid Center of Excellence (NICoE) at the Walter Reed National Military Medical Center provides the full spectrum of outpatient TBI services. One of the NICoE programs is a four week intensive outpatient program which leverages an interdisciplinary holistic patient and family-based approach to evaluate and treat service members (SMs) with unremitting symptoms from combat/mission related TBI and psychological health (PH) conditions. In 2012, after conducting many psychosocial intake assessments, a significant trend was observed among active duty service members and their partners. The trend involved the negative impact of emotional numbing and traumatic brain injury (TBI) on relationships. As a result, an intervention was created to address this issue with NICoE service members and families by providing education regarding coping and strategies for improvement.

Simultaneously, the Walter Reed National Military Medical Center (WRNMMC) Sexual Health & Intimacy (SHI) workgroup was established in March 2012 in alignment with WRNMMC's mission for the provision of holistic patient and family-centered care. The workgroup's goal is to provide sexual health education and treatment for wounded, ill and injured service members and spouses/partners. Workgroup members, consisting of nurses, nurse practitioners, social workers, physicians, occupational therapists, and pharmacists, hold weekly meetings to discuss concepts, craft clinical pathways and explore ways to develop a sustainable Sexual Health & Intimacy (SHI) service. In addition, educational trainings to various WRNMMC and Uniformed Service University of Health Sciences (USUHS) clinicians have been provided, incorporating strategies for addressing sexual health and intimacy issues with their patients and resources. Access to services at WRNMMC SHI clinic is by self-referral and/or provider referral (*see Figure 1 for clinical pathway*). Access to services at the National Intrepid Center of Excellence (NICoE) is part of the standard of care for traumatic brain injury.



**FIGURE 1  
WRNMMC CLINICAL SERVICE PATHWAY**



## **ADVOCACY STEPS IN PROGRAM DEVELOPMENT**

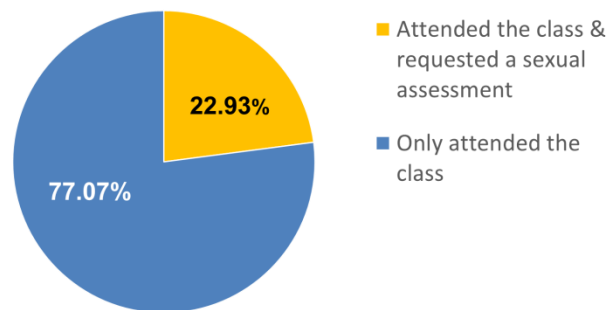
- In 2012 several staff members of WRNMMC including physicians, nurses, social workers, occupational therapists and physician assistants formed the WRNMMC Sexual Health & Intimacy Group. The group was designed to provide education to service members and their families regarding the impact of sexual health & intimacy in the wounded warrior population.
- Group members provided briefs/reports to the hospital Board of Directors and Executive Committee regarding the need for a Sexual Health and Intimacy Service at WRNMMC.
- Group members provide education to clinicians by making presentations to various hospital departments as well as to external customers.

A multitude of factors facilitated the progress of program development. These included: tracking of service member/partner interest in receiving information; the collaborative effort among SH&I group members to provide education in multiple locations; gaining assistance from key group members to help facilitate a home for the SH&I clinic within the Internal Medicine clinic, and; the support received from local/national organizations to assist group members in obtaining certification as sex therapist/counselors/educators providing services to the identified population.

At the same time, a number of factors surfaced that deterred program progress. Of major significance, there were no dedicated staffs. All SH&I work group members donate their time to provide this service. Developing this service/clinic is *collateral* duty for all members. Further issues that proved challenging included standardization of documentation and coding; making the SH&I service sustainable and not provider dependent; educating providers about how to increase their comfort levels when discussing sexual issues, and overall; generating administrative support for the proposed changes.

## THE PROGRAM TARGET POPULATION

The population addressed is active duty military members (95% male) and their families (primarily spouses/significant others). The National Intrepid Center of Excellence (NICoE) admits a new cohort of five service members each week for a total of about 250 patients per year since its opening in October 2010.



**Figure 2. Percentage of patients who either only attended the Relationships & intimacy class or attended the class and requested a sexual assessment**

At the NICoE, all SMs are scheduled to take the class but may not attend due to scheduling conflicts or illness. From May 2013 through May 2015, 376 of the 422 SMs scheduled chose to attend the class. Of the 376 SMs, 84 SMs requested either a follow up or individual/couple assessment (*refer to Figure 2; also see Table 2 for assessment model*). At WRNMMC, the SHI service received 50 referrals from May 2013 through May 2015. Of those, 45 were assigned to a clinician to begin the PLISSIT model of care (*refer to Table 2*). The remaining five patients were not seen due to retirement and a need for a different level of care.

**TABLE 1  
PATIENT DEMOGRAPHICS**

Table 1. Demographics		
	WRNMMC	NICoE
Age	38.98 ± 10.9	36.10 ± 8.0
Gender		
Male	56.5%	95%
Female	43.5%	5%
Martial Status		
Married	81.4%	60%
Single	9.3%	20%
Divorced	9.3%	20%
Service		
Army	31.8%	15%
Navy	20.5%	65%
Air force	11.4%	10%
Marines	29.5%	10%
PHS	2.3%	0%
International	4.6%	0%

**\*It should be noted that the U.S. Navy represents largest source of referrals for the NICoE program between 2013 and 2015.**

## **PROGRAM METHODOLOGY**

The Relationships & Intimacy class is a weekly educational offering at the NICoE addresses the impact of mild TBI (*mTBI*) and psychological health diagnoses on intimacy and sexual functioning. SM's attend the class during week two of the four week program and have the option to request an individual or couples intimacy assessment. As a patient and family centered program, the NICoE also offers a weekly intimacy class to spouses, partners and family members. The class was designed, in part to validate sexual functioning concerns and to affirm the goal of healthy sexuality. SM's, spouses, partners and family members who request an individual or couples intimacy assessment receive a brief version of the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model coupled with referral to local resources as needed.

Patients referred to the WRNMMC SH&I clinic participate in a brief intake assessment conducted by a SHI team member to determine the appropriate level of intervention by a sex educator, sex counselor, or sex therapist where the PLISSIT treatment model is utilized.

**TABLE 2**  
**SEXUAL HEALTH AND INTIMACY MODEL OF CARE**  
**WRNMMC and NICoE**

Table 2. Model of care and assessment utilized at WRNMMC and NICoE for Sexual Health & Intimacy	
WRNMMC – Plissit treatment model	NICoE – Brief setting model
<p>1. Patients referred by Medical Home provider, specialty clinics or via self-referral</p> <p>2. Initial intake conducted in 1-2 sessions to determine need and appropriate level of care.</p> <p>3. The PLISSIT Model of sex therapy is utilized with all patients. This model is based on the theory that majority of individuals can resolve their sexual-related problems. It follows a vertical structure, requiring greater knowledge and training as one moves up each level (Taylor &amp; Davis, 2007).</p> <p style="margin-left: 40px;">P – Permission  LI – Limited Information  SS – Specific Suggestions  IT – Intensive Therapy</p>	<p>1. SM and/or Spouse complete an Intimacy Safety Questionnaire</p> <p>2. Brief discussion of answers</p> <p>3. Get brief relationship history (single, married, how did you meet?, any children?, hx of Extramarital Affair/s?, hx of sexual trauma?, hx of post-partum?, etc)</p> <p>4. Get presenting problem (why did you request this session?, goal establishment). Additional questions are based on answers to this question. Ex. When did problem begin?</p> <p>5. Get brief sexual history (frequency, sources of arousal now and in the past, monogamous?, frequency of orgasm - especially for females, erectile dysfunction?)</p> <p>6. identify possible barriers to goals</p> <p>7. provide education and help broker compromises</p> <p>8. Provide resources as needed</p>

## ADVOCACY OUTCOMES

The goal of the WRNMMC Sexual Health & Intimacy Work group is to have a (sustainable) dedicated staff of sex therapists, counselors and educators to provide routine assessment and treatment for sexual and intimacy related issues with wounded warriors and their families. Additionally, our intent is to provide continued education to WRNMMC staff/providers regarding how to discuss/screen sexual health related issues with patients. In advocating for this intervention, the following accomplishments have occurred to date:

- The SH&I workgroup members have successfully secured scholarship funds from Semper Max and the Bob Woodruff Foundation to pay for clinical supervision towards securing certification as sex therapists, counselors and educators;
- Since 2012, members of the SH&I work group have provided education to WRNMMC inpatients and outpatients in group settings and through one-on-one interventions;
- We have worked to standardize our screening by utilizing the Intimacy Safety Questionnaire (ISQ), and investigating PROMIS Sexual Function and Satisfaction Measure, and Female Sexual Functioning Index;
- Progress continues on solidifying a clinical pathway, carefully balancing patient need with current resources;

- Developed a weekly Relationships and Intimacy class for NICOE service members and families, who also have the option to request an intimacy assessment (individual or couple);
- Sexual Health & Intimacy workgroup members have made several presentations to internal and external customers regarding the need for standard assessment of intimacy/sexual functioning, and ways to refer patients to the SH&I service;
- Facilitated a comprehensive assessment of need which determined a more inclusive and systematic provision of services should be available command-wide;
- Secured training and certification funding for workgroup members to become sex therapists, counselors and educators;
- SH&I training has been incorporated in the training of medical students at the USUHS, and;
- SH&I services are now located in Integrative Health & Wellness Services to increase accessibility and reinforce importance of sexual health among other indicators of health.

Securing funding toward certification was a significant accomplishment, however the larger accomplishment has been normalizing the sexual/intimacy conversation for providers and patients. Over the past two to three years, many WRNMMC providers have started discussing sexual functioning more regularly with their patients. SH&I work group members are consulted more frequently regarding sexual issues. Other Military Treatment facilities have expressed an interest in duplicating the efforts of the WRNMMC SH&I work group.

Our advocacy initiative remains a work in progress. Our desired end state would consist of all medical/psychiatric providers routinely screening for intimacy/sexual wellness just as they screen for pain and SI/HI. Providers would have the ability to refer patients to a fully staffed service dedicated to assessing and treating a variety of sex/intimacy related issues. This model would eventually be adopted by all military treatment facilities in the country.

As typical in the public and private sectors, professionals are faced with having to provide more with less; we are no exception. One factor influencing why our end-state/goal has not been achieved is the significant responsibilities that most work group members carry as a part of their primary work assignments. Additionally, many decisions related to this program have not only clinical, but also legal implications that must be considered. Consulting is warranted with a multitude of hospital personnel including credentialing, Judge Advocate General [JAG] and senior leadership as well as AASECT (American Association of Sex Educators Counselors and Therapists) to determine next steps. This multi-layered process can be anticipated to take time.

## **THE FUTURE**

As we look toward the future for our program, we have identified a variety of prioritized goals and activities on which to focus. These include:

- SH&I work group members receiving ongoing training and supervision to achieve and maintain certification as sex therapists, counselors and educators;
- Continued development of Standard Operating Procedures (SOP) for the SH&I service and the clinical pathway;
- Refinement and possible expansion of our referral process to include treatment centers within the National capital area;
- Analyze information gathered from standardized tools/methods and publish findings;
- Collaboration with internal/external entities to conduct research, and;
- Teach/implement solidified model to other military treatment facilities for implementation as appropriate.

## **RECOMMENDATIONS**

Our experience in advocating for and then initiating this patient program has led us to propose several recommendations for others considering program development. We consider these as crucial steps or components for success:

- Identify trends/patterns of unmet needs and develop a reasonable action plan for addressing goals;
- In planning, start small and then try to identify others within your organization who share your vision to gain support;
- Develop a tracking system to document trends/progress;
- Provide updates/briefs to leaders of your organization for transparency and to garner support;
- Make sure your initiative includes a plan for sustainability, and;
- Report outcomes.

## **SUMMARY**

The NICoE relationships and intimacy offerings, as well as the WRNMMC SHI clinic has experienced positive gains such as continued support from command leadership to provide this education modality to patients, families and loved ones. As with any new endeavor, challenges exist including: no dedicated personnel; lack of dedicated space, and; continuing education/AASECT certification opportunities for additional staff as demand for services grows. Finding solutions to these challenges are crucial to our ability to create a sustainable service where providers can refer patients for assessment and treatment.

Our future goals include developing a standardized screening process to assess intimacy and sexual functioning needs of active duty service members at WRNMMC, to eventually be implemented at Military Treatment Facilities (MTF's) nation-wide. Advocacy efforts not only include creating awareness regarding the need for a standard SH&I screening among the active duty military population, more importantly it includes the empowerment of patients and family members to advocate for themselves.

Advocacy is a fundamental component of our role and this program reflects the efforts of staff to identify an important service need and then implement a viable response for service members and their loved ones.

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# YALE-NEW HAVEN HOSPITAL'S ADVOCACY FOR THE HOMELESS

*Paula Crombie, LCSW and Michael Ferry, LCSW*

*"[O]nce they discharged me, I had nowhere to go. I would have had to go back to a shelter or the street if I had not been able to come here." ~ Homeless Patient*

## INTRODUCTION

While there have long been services for the homeless in New Haven and in some of its surrounding towns, it often takes advocates to recognize that the existing system is no longer working as well as it should be, and to push for change. This chapter documents the series of events that led to the implementation of a Medical Respite program at Yale-New Haven Hospital, and the role that advocacy played in addressing homeless individuals' previously unrecognized needs both within medical settings and in the larger community.

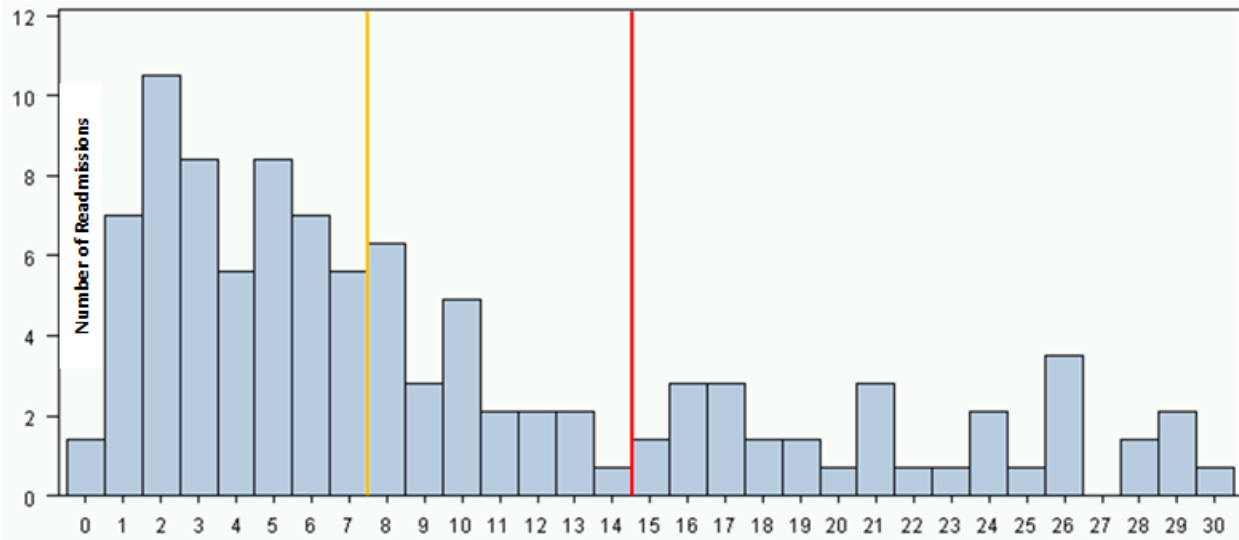
Advocacy often begins with small steps and quiet resolutions that, when successful, gradually take on a much greater scope and reach far deeper into people's lives than may have been imagined initially. This has certainly proven true of Yale-New Haven Hospital's efforts to assist the hospitalized homeless in securing a setting with which to recuperate from their injuries or illnesses. Yale-New Haven Hospital is a 1500-bed tertiary care hospital located in south-central Connecticut. It is part of a five hospital system covering southern Connecticut. In the greater New Haven area of Connecticut, point-in-time surveys identify approximately 700 Housing and Urban Development (HUD)-defined chronically homeless individuals at any given time. In Yale-New Haven Hospital, many more patients self-identify as homeless, while not necessarily meeting HUD criteria. During 2014, approximately 800 admitted patients self-identified as homeless which, when repeat individuals are accounted for, resulted in 475 unique patients being identified as lacking stable housing. After being hospitalized, even when resources are available, many homeless individuals find it challenging to properly care for themselves or to access the resources to which they are referred. This results in an increased volume of emergency department visits, longer recovery times during inpatient lengths of stay, and a preponderance of readmissions to inpatient care within 30 days following each hospitalization.

## BACKGROUND

Our advocacy efforts can be traced back to the work of one of New Haven's Yale University scholars, Kelly Doran, MD, MHS, of the Robert Wood Johnson Clinical Scholars



Program at Yale University. She participated in a task force looking at the post-hospitalization readmission rate for New Haven’s homeless, with an emphasis on those who might have qualified for medical respite care. Using data collected during the spring and summer of 2012, her study found that of the 113 individuals reviewed, 50.8% of them were re-admitted to inpatient care, and an additional 3.0% were readmitted for observation, while a further 27.0% sought and received treatment from the Emergency Department, all within 30 days of discharge from a prior admission. Of the 53.8% of readmissions (inpatient and observation), 75% of them occurred within two weeks.



Comparatively, only 18.7% of Medicaid patients (including the homeless) were hospitalized for inpatient care within 30 days of their discharge.

With the attention brought to readmissions by the Patient Protection and Affordable Care Act of 2010, the Social Work Department at Yale-New Haven Hospital recognized this as an opportunity to advocate for the homeless, a population that has long been under-identified and under-served. Social Work soon presented the results of Dr. Doran’s study to hospital and community leaders. Now able to recognize the impact that the homeless were having upon local and fiscal resources, they welcomed the expertise, networking, and advocacy that Social Work had to offer. The Social Work Department took a leadership role in organizing and developing support for a medical respite program and networking amongst the community, in an effort to find supporters willing to assist in moving the process forward.

In partnership with a local shelter that had been receptive to Dr. Doran’s findings, a twelve-page booklet was soon created, “*Columbus House Respite Program: A Solution for Patients who are Homeless in New Haven.*” Columbus House is a 501(c)(3) non-profit agency providing emergency shelter to individuals experiencing homelessness. This publication was an important reference for the Yale-New Haven Hospital/Columbus House task force as it planned for a medical respite pilot program. The booklet explained how medical respite programs are stay-in locations where homeless patients can recuperate from illness or injury while receiving

home nursing care before returning to their prior circumstances or, better yet, transitioning into permanent housing.

A task force was developed to search for funding. Through the advocacy efforts of the Yale-New Haven Hospital and Columbus House staff, a key legislator was identified as a champion, and agreed to sponsor Connecticut bill SB1087. Throughout the legislative process, testimony was submitted and Connecticut State Senator Toni Harp worked with the Department of Housing to create a line item budget for a pilot program. As a result of these efforts, Connecticut Governor Daniel Malloy signed a bill funding the medical respite pilot program for five years.

## **OVERVIEW: MEDICAL RESPITE PROGRAM**

The purpose of our Medical Respite Care program is to provide safe, adequate housing during the recuperative phase for homeless individuals in our community. The Medical Respite Care program opened on October 7, 2013. Yale-New Haven Hospital and Columbus House jointly administer the program through a comprehensive Memorandum of Understanding.

The physical resources of Medical Respite include twelve beds on the third floor of Columbus House. The program services include increased oversight and transitional services for patients being considered for the program, twenty-four hour supervision, navigation to medical services, and case management for housing, employment, and income programs. Patients also receive long-term linkage to homeless services in the region. A multi-disciplinary, multi-agency community care team meets regularly to track and oversee the care of Respite Care patients. Representatives from Yale-New Haven Hospital (physicians, social workers, care managers, pharmacy), Columbus House, Visiting Nurses of South Central Connecticut, Continuum of Care (home nursing agencies), Cornell Scott-Hill Health Center (urgent care clinic), and the hospital's primary care clinics meet weekly, to address front-line patient care issues immediately and collaboratively. This is made possible through the use of a comprehensive release of information (*see attachment I*).

### *The Impact of Advocacy upon Interviews and Documentation*

Many of our homeless patients are open about their lack of housing. Others are hesitant, due to concerns of being treated differently. Within the first two months of the program, we realized that our methods of patient-finding for referral were inconsistent, included stale data, and did not take full advantage of the many different disciplines that interact with and document on each patient. To address this, we began by identifying consistent locations in the medical record in which each discipline identifies patients as homeless. We found that there are three locations in the electronic medical record we could use: addresses collected by our admitting department, the diagnoses entered by a physician, and notations entered during nursing and social work assessments. Our next step was to train doctors, nurses, social workers, and care managers to make housing an interview and assessment topic, and then guide them into documenting their findings in a consistent manner. Among the questions we encourage staff to ask patients are, "Where have you been living for the past two months?" "Is this reliable housing

that you own, rent, or stay in as part of a household?” and “Are you able to receive a visiting nurse there?” With staff now documenting in a consistent manner and location, we then developed reports scanning the medical chart of every patient in hospital to seek out their data. Our automated daily reports now find 50% more self-identified homeless patients within the hospital than compared to prior methods.

### *Engagement of Patients and Staff*

Once patients are identified as homeless, they are referred to the unit social worker who will do a thorough assessment of the patient and consult with the medical team regarding their anticipated medical needs after discharge. If the patient’s medical needs do not require a stay in a short-term rehabilitation facility and a period of recuperation is recommended before returning to the street or standard shelter services, the patient will be introduced to the Medical Respite program and its services, and encouraged to sign a release of information form, which allows sharing of information among all involved agencies. Some of our patients have concerns about utilizing local shelters, and need encouragement to trust and use the Medical Respite program. In the hospital, we developed and printed brochures for staff to share with our more cautious patients (see attachment). The release form is then attached to an application which is electronically transmitted to the Columbus House shelter. After reviewing the application, their patient navigator will interview the patient and advise whether they are able to accept the patient. If so, referrals are sent out to a local clinic and home nursing agencies.

There is a much work that must be done prior to physically discharging the patient. While more than three-quarters of our homeless patients had Medicaid, many others were unable to obtain the medications and other supplies that they required upon discharge. The involvement of Yale-New Haven Hospital’s pharmacy was a significant development, as they assisted us by establishing a free care fund through which Medical Respite patients without insurance or monies could secure prescriptions, supplies, and over-the-counter medications.

Another challenge we faced was the implicit assumption by medical staff that homeless individuals have all the resources and abilities that any other patient would have, just not a home in which to sleep and cook. It was gradually realized that there is a need to verify that a patient has the insurance that they believe they do, or have the medications in their backpack that they think they do, or can actually pay for over-the-counter medications and supplies. Because of these and other similar issues, we found it necessary to create a discharge checklist specifically for our Medical Respite patients (see attachment). Social workers have been essential in sensitizing medical staff to the increased needs of the homeless, and ensuring that all the details for a successful discharge are addressed. This involvement has contributed significantly to further reducing our readmission rate for this population. Upon discharge, a patient navigator will transport the patient to the shelter and the hospital apothecary will deliver all prescriptions.

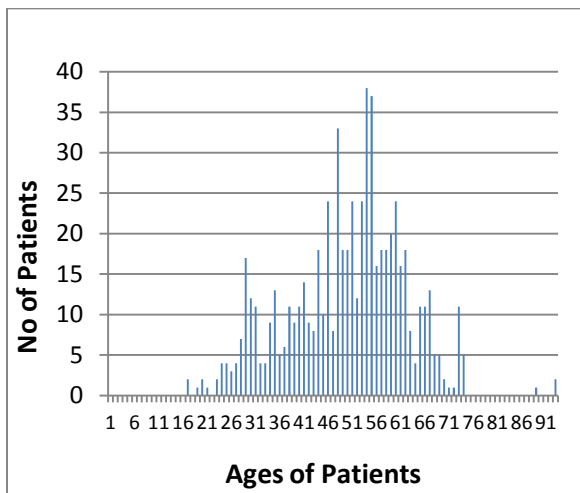
Among the ongoing challenges are patient motivation and cooperation. Having secured a safe, reliable location in which the homeless could recuperate, many of these patients’ continue to have ongoing social and behavioral needs, and a long a history of using unhealthy coping methods. Many patients wrestle with staying clean and sober during their stay in Respite. And not all patients’ primary motivation is to get better. One of our early patients woke us up to the

importance of assessing for ability and motivation to cooperate with medical and shelter staff recommendations, when it became obvious that his priorities involved exacerbating his illness in an effort to secure attention and amenities. We continue to adjust how the program operates with each lesson learned.

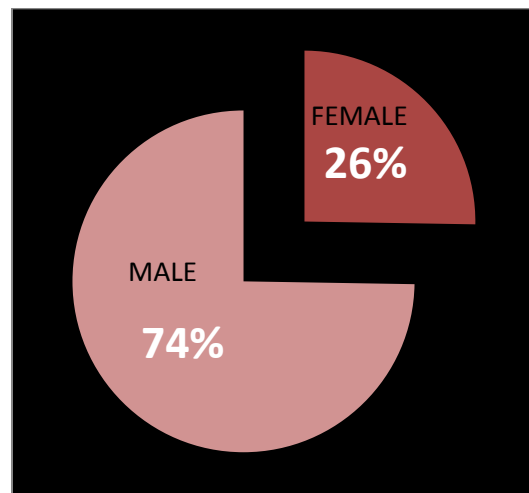
Patients are provided with case management and housing services by the shelter and with medical care by visiting nursing agencies and local clinics. As mentioned previously, this process is monitored on an ongoing basis during weekly care team meetings, led by staff from the Department of Social Work. Most patients are discharged to different forms of housing approximately six weeks after discharge.

### *Description of Patients Served*

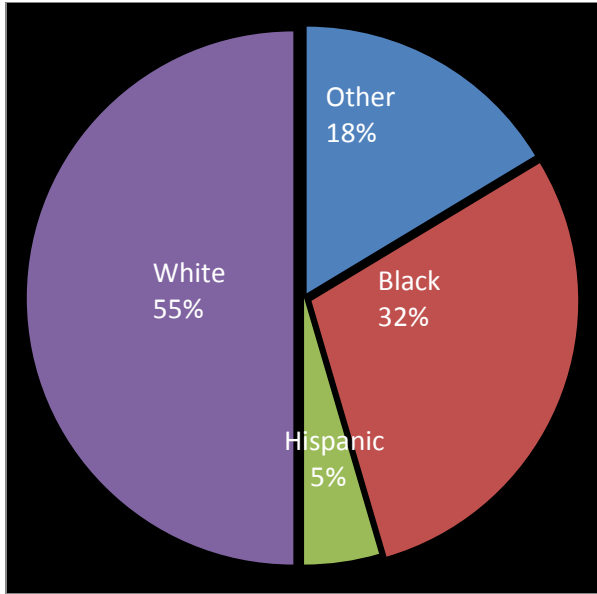
As we track our progress with the program, our confidence in its functioning and its results continue to grow. Upon concluding the program's first year, we found that the Respite program had provided care to 58 of 475 unique self-identified hospitalized homeless individuals.



The average age of our homeless patients is 49.0 years.



The breakdown by sex is one-quarter female and three-quarters male.



Our most recent screenings have identified our admitted homeless population as nearly one-third Black, five percent Hispanic, just over half as White, and the remainder being Asian, Pacific Islander, or of mixed race.



Measured separately, we found that between 54% of our clients were abusing alcohol, 52% were using illicit drugs, and 59% had acquired a mental health diagnosis (even if not currently experiencing symptoms). When considering these items in combination, 91% of our self-identified homeless were compromised by mental health difficulties, alcohol abuse, or drug use.

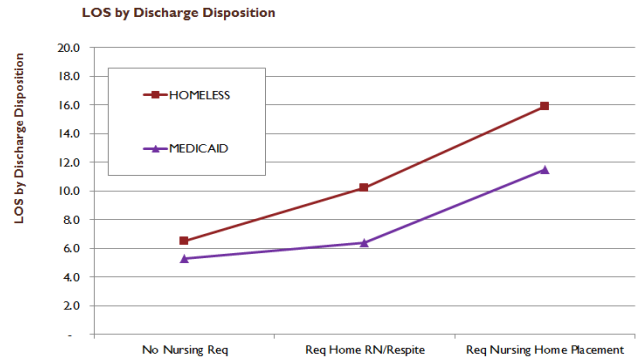
When examining our self-identified homeless patients health and interactions with the health care system, the most common diagnoses upon admission were diabetes, alcohol intoxication, and chest pain. Less than 40% of our patients had a primary provider or clinic upon admission. We found that upon discharge from the hospital, the average number of medications prescribed at discharge was 6.7, however, this obscures a range of no medications to as many as 22! Approximately 98% of the self-identified homeless had some form of medical insurance, the most common being Medicaid (81.5%) and Medicare (14.9%). Just over one-third of the self-identified homeless are aged or disabled.

### *Program Outcomes*

From a hospital perspective, after going beyond numbers of people served, among the more important measures of success include length-of-stay, post-hospitalization ED/observation visits, and re-admission rates. Our primary comparison groups are the adult Medicaid population, the self-identified homeless, and those admitted to Medical Respite (who by our definition require home nursing).

## 1. Hospital Length of Stay by Discharge Disposition

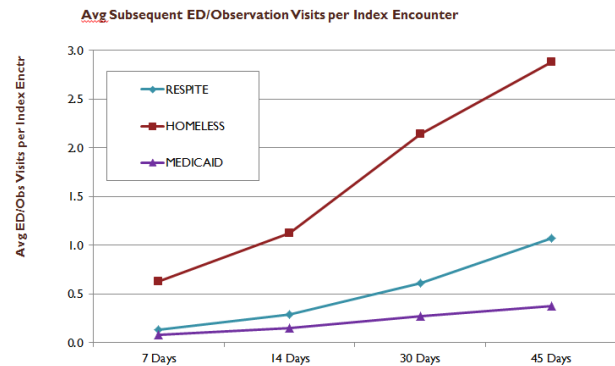
	Discharge Disposition		
	No Nursing Care Recommended	Required Home Nursing or Respite Care	Required Nursing Home Placement
<b>All Medicaid (Age &gt;17)</b>	5.3 Days	6.4 Days	11.5 Days
<b>Homeless (Age &gt;17)</b>	6.5 Days	10.2 Days	15.9 Days
<b>Difference</b>	1.2 Days	3.8 Days	4.4 Days



From the above table and graph, we see that all groups of homeless patients have longer lengths of stay, which is made more pronounced as patients' medical issues increase in severity.

## 2. Post-Hospital Discharge ED/Observation Visits

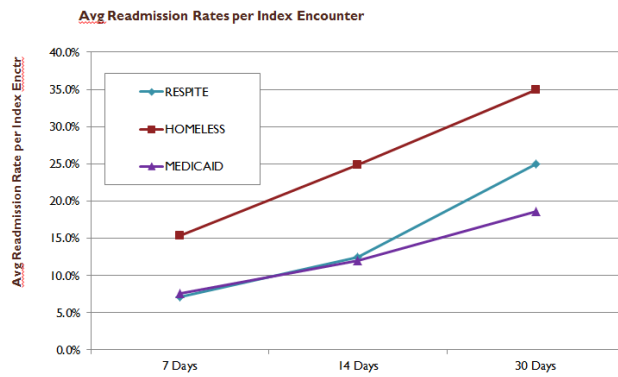
Population Time	All (age > 17) Medicaid	Homeless Medicaid Patients	Respite Medicaid Patients
<b>45 days</b>	0.4	2.9	1.1
<b>30 days</b>	0.3	2.1	0.6
<b>14 days</b>	0.1	1.1	0.3
<b>7 days</b>	0.1	0.6	0.1



This table and graph show that with Medical Respite, the number of ED/observation visits can be managed much more closely to that of the adult Medicaid population. We recently initiated behavioral guidance to reduce unnecessary patient-initiated visits to the emergency department.

### 3. Hospital Readmission Rates

Population Time ↓	All (age > 17) Medicaid	Homeless Medicaid Patients	Respite Medicaid Patients
30 day	18.6%	35.0%	25.0%
14 day	12.0%	24.8%	12.5%
7 day	7.6%	15.4%	7.1%



Similar to the prior illustrations, this table and graph show that with Medical Respite, the number of re-admissions can be managed much more closely to that of the adult Medicaid population.

## **THE FUTURE**

We have recently begun screening and admitting patients to the Medical Respite program from the emergency department and, on a case-by-case basis, may accept patients from our affiliated clinics so as to prevent a hospital admission. As we share our successes, and the benefits of the program are appreciated by others, we are organizing a statewide group to consider Medical Respite programs outside of our greater New Haven catchment area. As part of this, we have been communicating with our state Department of Social Services to create a reimbursement process, so as to include those patients accepted into the Respite program with the intent of preventing an admission. Lastly, while very few individuals have been counseled out or chose to leave due to alcohol/drug use, we have been reviewing our substance abuse policies so as to implement a protocol of least harm when use is discovered while in the program.

Among our continuing challenges is providing services to the undocumented. We have succeeded in developing a free care program and continue to accept patients regardless of insurance status. There are no long term housing, employment, income solutions for such individuals. It has also proven very challenging to connect the recently incarcerated, most notably sex offenders, with services and ultimately housing. We continue to put effort into reducing inpatient length of stay for Respite patients. Their hospitalizations remain longer than that of other patients, in part due to the extra effort now mandated by our discharge checklist process, which ensures that these patients will be connected to all of the resources and services they require, in addition to the extra steps inherent in the process of application and transfer to Respite.

## **SUMMARY**

One of our early Respite patients who agreed to be interviewed, and have her words published, had this to say about Medical Respite, “I’m just grateful for this place. The nurses come to see me every day, I have my own room and I love the structure. It’s wonderful to have a roof over my head.” This is in stark contrast to what she would have experienced prior to the program being established, “...once they discharged me, I had nowhere to go. I would have had to go back to a shelter or the street...” With Medical Respite and the growing community commitment to end the plight of chronic homelessness, there is now confidence that not only New Haven, but the state of Connecticut, is well-positioned to end the homelessness of veterans by the end of 2015, and eliminate chronic homelessness by the end of 2016.

As social work leaders engaged with our community, we’ve seen the benefit of managing a specific high-risk patient population. By recognizing homelessness as an important determinant of poor health, stretching our sphere of involvement beyond hospital walls, and joining with service providers not typically considered part of the healthcare community, we



have learned many lessons and experienced even more success. The Social Work Department at Yale-New Haven Hospital is now well-positioned to present additional proposals with which to influence the public health paradigm, improving the health outcomes of other needy populations.

The changing health care environment is a unique opportunity for social work leaders to represent the profession, as health care organizations create strategies for continued growth and later stabilization. The Social Work Department of the Yale-New Haven System is well respected for our clinical work and now for our strategic initiatives. This is the time for social work leaders to take risks and participate in shaping the future of our organizations. At Yale-New Haven Hospital, we are excited and proud to be an important part of this strategic process.

## REFERENCES

- \_\_\_\_\_. (December 20, 2013). *A Place to Heal for the Holidays*. Retrieved February 17, 2015 from: <http://www.rwjf.org/en/library/articles-and-news/2013/12/a-place-to-heal-for-the-holidays.html>.
- Doran, Kelly M; Ragins, Kyle T; Iacomacci, Andrea L; Cunningham, Alison; Jubanyik, Karen J; Jenq, Grace Y. The revolving hospital door: hospital readmissions among patients who are homeless. *Medical Care*, Vol 51, Number 9, September 2013. pp. 767-773.
- \_\_\_\_\_. *Columbus House Respite Program: A Solution for Patients who are Homeless in New Haven*. (December 21, 2012). New Haven, CT: Columbus House Respite Program.

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**Yale-New Haven Hospital/Columbus House Medical Respite Care Program  
Participation Agreement and Authorization for Access/Release of Information**

PATIENT/CLIENT NAME: \_\_\_\_\_ DATE OF BIRTH: \_\_\_\_ - \_\_\_\_ - \_\_\_\_

YNHH Medical Record# \_\_\_\_\_ NAME OF FRIEND/NEXT-OF-KIN ETC. \_\_\_\_\_

ADDRESS/PHONE NUMBER (if applicable): \_\_\_\_\_ May I leave a message at this #?  Yes  No

This document authorizes Yale-New Haven Hospital (YNHH) and Columbus House Medical Respite Care Program to use, share and disclose protected health information (PHI) of the person named above with one another, as well as with other entities participating in the Medical Respite Care Program. These entities include, but are not limited to, Columbus House, YNHH and its Primary Care Center, Cornell Scott-Hill Health Center, Visiting Nurse Association of South Central Connecticut, Continuum of Care and The Apothecary (collectively the "Participants") for purposes of screening for participation in the program, as well as ongoing care and treatment.

**I authorize YNHH, as well as the Participants named above, to release the information from my medical records as necessary and to obtain information from:**

Columbus House Medical Respite Care Program, 586 Ella Grasso Boulevard, New Haven CT 06519 Phone: 203-401-4400

The person to be contacted at YNHH regarding medical questions or concerns is \_\_\_\_\_ Phone: \_\_\_\_\_  
(name of social worker or care manager)

**INFORMATION TO BE RELEASED OR OBTAINED (IN EITHER VERBAL OR WRITTEN FORM) may include:**

- Relevant Social and Health History
- Medication Required Following Discharge
- Protected Health Information affecting home care needs
- Information related to necessary contact precautions

1. I understand that this authorization will expire one year after I have signed this form, or other date as specified: \_\_\_/\_\_\_/\_\_\_
2. If I change my mind about allowing YNHH and Columbus House Medical Respite Care Program to share my information, I will tell YNHH and Columbus House in writing. This change will be effective on the date the organization receives it but will not affect anything that has already happened.
3. I understand that information used or disclosed as part of this authorization may be subject to re-disclosure by the recipient and may no longer be protected by privacy regulations.
4. I understand that I am not required to sign this form in order to receive treatment or payment for my care.
5. I understand that information to be released or obtained may include mental health information in accordance with CGS 52-146(d), substance abuse treatment information in accordance with 42 CFR 2.1-2.67, and/or HIV/AIDS-related information except as below:

- No Mental Health
- No Substance Abuse treatment information
- No HIV/AIDS information

\_\_\_\_\_  
Patient Signature Date \_\_\_\_\_ Time \_\_\_\_\_

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Parent/Legal Guardian/Authorized Person Date \_\_\_\_\_ Time \_\_\_\_\_

\_\_\_\_\_  
Relationship to Patient

**PATIENT MAY RECEIVE A COPY OF THIS FORM AFTER SIGNING  
(White - YNHH Medical Record, Yellow - Columbus House MR Program, Pink - Patient)**



Permanent Address
  Temporary Address
  Confidential Address

Address: LIVES IN CT  
NO FIXED ADDRESS

City (or ZIP):

State:  ZIP:

County:

Country:

Contact Information:
 

	Number Type	Number	
1	Home Phone	000-000-0000	
2	Work Phone		
3	Mobile	000-000-0000	
4			

E-mail:

Comments: PT IS HOMELESS 586 ella grasso blvd, colombus house

Non-Hospital Problem List			Date Reviewed: 3/31/2014	
	ICD-9-CM	Priority	Class	Noted
Alcohol withdrawal	291.81			3/26/2014
Atrial fibrillation with rapid ventricular response	427.31			11/24/2013
Chronic pain syndrome	338.4			11/24/2013
Community acquired pneumonia	486			11/24/2013
Nicotine dependence	305.1			11/26/2013
Alcohol abuse	305.00			11/27/2013
Homelessness	V60.0			11/27/2013
Atrial fibrillation	427.31			2/4/2014
Atrial fibrillation with RVR	427.31			3/3/2014
Fibromyalgia	729.1			2/4/2014
Knee strain	844.8			3/3/2014
Hypertension	401.9			Unknown

Housing / Transportation

Living Arrangements for the past 2 months
 

apartment	assisted living facility	automobile	condominium
correctional facility	emergently doubled-u...	extended care facility	foster care
group home	hotel/motel	single-family house	multi-family house
independent living faci...	mobile home	residential facility	rest home
rooming house	shelter	other	no permanent address

Living Arrangements Comment:

Able to Return to Prior Living Arrangements following Visit/Discharge:
 

yes	no	temporarily	other	unable to a...
-----	----	-------------	-------	----------------

Ability to Return to Prior Living Arrangement Comment:

Able to Receive Visiting Nurse at Prior Living Arrangement:
 

yes	no	temporarily	other	unable to a...
-----	----	-------------	-------	----------------

Able to Receive Visiting Nurse Comment:

Environmental Concerns:
 

no concerns	no permanent re...	insects/pests	air conditioning	electricity
heat	natural gas	heating oil	indoor plumbing	lead
lighting	mold	no back-up gene...	phone	running water
smoke detector	refrigeration	chipping paint	unsafe stairwell	broken windows
other	unable to assess			

### What does it mean to lack suitable housing?

People who lack suitable housing may be living at a shelter, on the street, in a car or in some other location not meant for habitation. It may also include people who are living with friends or family, or temporarily staying in a motel/hotel and unable to secure permanent housing arrangements.



### What is the goal of Medical Respite Care?

The goal of the Medical Respite Care program at Columbus House is to improve the health and well-being of adults who lack reliable housing. For those who become ill enough to require hospitalization at Yale-New Haven Hospital, it is a means of reducing their length of stay at the hospital and assisting them as they recover, so that re-hospitalization will not become necessary. The program also connects patients with supportive housing and other services to break the cycle of homelessness.



586 Ella Grasso Boulevard  
New Haven, CT 06519  
[www.columbushouse.org](http://www.columbushouse.org)

For more information about the Medical Respite Care program, please ask to speak with the social worker or care manager on your unit.

## Medical Respite Care



The Medical Respite Care program is funded by the State of Connecticut and supported by Columbus House, Yale-New Haven Hospital, Cornell Scott - Hill Health Center and local home nursing agencies.



## Medical Respite Patient Discharge Checklist

- Is the patient medically stable for discharge?  
.....
- Have prescriptions been prescribed for this patient?
- Have the prescriptions been reconciled?
- Are prior medications being continued, accounted for, and are they available to the patient?
- Does the patient have active prescription coverage with which to fill any new or refill any ongoing prescriptions?
- Will the active prescription coverage cover all of the new medications being prescribed?
- Is there a method with which to secure non-covered medications?
- Will the new and ongoing prescriptions last until the patient's next appointment?
- Have the prescriptions been e-prescribed to the Apothecary at SRC?
- Has the Apothecary been notified that the above prescriptions belong to a Medical Respite patient?
- Has a delivery method been verified for prescriptions sent elsewhere, e.g. narcotics?  
.....
- Are wound care or diabetic supplies needed for this patient?
- Can any wound care or diabetic supplies be provided from the patient's room?
- Are additional wound care or diabetic supplies covered by insurance?
- Is there a means with which to secure additional wound care or diabetic supplies?
- Has a delivery method been verified for the additional wound care or diabetic supplies?  
.....
- Does the patient have a primary physician or a clinic for follow-up care?
  - If so, has the physician or clinic been contacted regarding this hospitalization?
  - If not, has the Cornell Scott-Hill Health Center or the Primary Care Center (at York St) been contacted to accept your patient as a new client?
- Has a 7-day follow-up appointment been made for the patient with the physician or clinic?
- Have all necessary lab draws been scheduled?
- Has a copy of the patient's completed Logisticare Forms been faxed to Columbus House for follow-up?  
.....
- Does the patient have need for skilled home nursing care?
- Has the patient/patient navigator been asked for their preference of home nursing agency?
- If so, has a home nursing agency been contacted for services?
- Has the patient's W-10 been provided to the home nursing agency?
- Has the home nursing agency accepted the patient for services?