

# **Transformation of Care Systems: Lessons Learned in Prison Research**

Janice Penrod, PhD, RN, FGSA, FAAN & Erin Kitt-Lewis, PhD, RN

07 February 2018

## **Summary**

This article provides an overview of lessons learned in the transformation of end-of-life care delivery in prison settings. The evolution of the program of research provides insights into the pathway toward the social innovation of prison work. The context of the prison setting is presented to provide an overview of the challenges faced in this care delivery system. Following a summary of the key phases of the program of research, relevant considerations for nurse scientists working to transform healthcare systems in any setting are discussed.

## **Article**

As nurses work to transform the health care system, we face a myriad of issues. The aging of the population has shifted our attention to chronic co-morbidities and geriatric syndromes. End-of-life care and related

decision-making have become more critical considerations as advanced medical treatments continue to extend life. Extending life escalates a focus on functional capacity and quality of life issues. Interdisciplinary teams are learning how to best communicate with each other to promote comprehensive high-quality health care. These issues and others are prominent in the free world as public media draws our attention to these significant concerns. Still, far less attention has been paid to a large, vulnerable population of incarcerated people facing similar system-wide issues. This article examines some of the lessons learned in our work to transform care delivery by changing the culture of care in a restrictive, challenging system --prisons. These lessons are relevant considerations for nurse scientists working to transform healthcare systems.

## **The Pathway to Innovation**

Our preliminary studies explored end-of-life care from the perspective of providers and care recipients in the context of care delivery systems in the free world. We identified key components of the culture of care manifest in the system of care delivery for patients and families in three distinct illness trajectories: heart failure; advanced cancers; and amyotrophic lateral sclerosis.<sup>1</sup> These illnesses were targeted due the differences in course of illness and related life/death expectations. It became clear that the provider networks' shared values and beliefs

shaped the culture of care in a given delivery system, and that culture significantly influenced the patient/family experience.<sup>2</sup> Despite the fact that the average life expectancy was about the same in each illness trajectory, the course toward and through end-of-life care was dramatically different for those receiving care in the three different delivery systems.

In sum, culture mattered -- values and beliefs were implicitly and explicitly communicated by providers during routine interactions. Patients, families, and care providers integrated values into the perception of the illness (i.e., terminal v. life-limiting); course of treatment (i.e., iterative cycles of fighting the war v. working through decline while enhancing quality of life), and expectations of the future (i.e., anticipated v. sudden death). The culture of care also influenced the timing and acceptability of the provision of end-life care.

Based on this work, the notion of re-shaping the culture of care as a strategy for transforming care delivery systems to enhance end-of-life care was hatched. We seized an opportunity to take an alternate route in our program of research and the social innovation was launched. We argued that the context of corrections care was the ideal setting for understanding strategies for re-shaping the culture of care to enhance end-of-life care. The prison system is complex and is fraught with strongly held values and beliefs. Perhaps more importantly, prisons are facing a demographic shift that is similar to the free world. The

prison system was a unique setting in which to study culture change to enhance end-of-life care delivery.

## **The Problem: The Context of Prisons**

Most people imagine a prison population comprised of young, strong men. The facts tell us that this image of prison is not reality. In 2015, approximately 19 percent of the 2.1 million inmates in the U.S. state or federal correctional system were age 50 years or older.<sup>3</sup> Still, many think, 50 is not "old" and many 50-year-olds are very robust. In the prison setting, chronological age and biological age are often quite different. As early as the 1990's Aday described accelerated aging of inmates and suggested the typical inmate in their 50s have a physical appearance of free citizens 10 years older.<sup>4</sup> More recent research suggests that prisoners over the age of 50 years have a health profile of community-dwellers 12 years older and are significantly more likely to have one or more chronic health conditions than their community-dwelling counterparts.<sup>5, 6, 7</sup> Older adult inmates, typically categorized as those aged 50 years and older, are the fastest growing inmate cohort in the federal system.<sup>8</sup> Between 1993-2013, the number of state prisoners age 55 years and older has increased 400 percent.<sup>9</sup>

Three main factors contribute to the aging inmate population. A greater proportion of older inmates are serving longer sentences; for example, life without parole means life in prison until death.<sup>10, 9, 11</sup> The number of older

adults admitted to correctional facilities have increased.<sup>9</sup> Restrictive policies of early release and parole lead to inmates aging and dying in prison.<sup>10, 11</sup> If current trends continue by the year 2030, 33 percent of the U.S. prison population will be age 55 years or older.<sup>12</sup>

The continued rise in the number of older adults living in the correctional system creates new challenges and financial strains for the criminal justice system. The Federal Bureau of Prisons alone spent \$881 million dollars (19 percent of total budget) to incarcerate older inmates.<sup>8</sup> In 2011, nationwide, state prisons health care spending totaled 7.7 billion dollars.<sup>13</sup> Health care costs for older adults are three times higher than younger prisoners.<sup>10, 14</sup>

It is important to realize that the criminal justice system is responsible for the care, custody, and control of inmates. That is, once incarcerated, inmates are entitled to receive health care at the expense of the prison system.

Medicare, Medicaid, or private insurance does not reimburse the care of inmates. The increasing number of older adults in prison has placed new burdens on the system. In 2011-2012, 50 percent of the corrections population reported having at least one chronic condition.<sup>15</sup> Chronic conditions are three times more prevalent in the corrections population compared with free-world population.<sup>14, 15</sup> The correctional health care system is underprepared to provide cost-effective quality care for the growing older adult population.<sup>16</sup>

# Approach

Correctional systems must find way to provide high quality, cost effective care with limited resources. Beyond quality and cost considerations, understanding the culture and the unique challenges faced by correction personnel is critical. The corrections environment presents unique challenges to implementing best practice initiatives; specifically, maintaining custody and control while addressing care needs.<sup>17</sup> This program of research focused on the stimulating a change in culture that would promote a change in care delivery in the prison setting.

In the first study, Participatory Action Research (PAR) approaches were used to understand the culture of care and transform the delivery of end-of-life care (EOL) in correctional settings.<sup>18</sup> PAR is a methodological approach that promotes sustainable change through research-participant collaboration. In the first phase of the project, the team focused on understanding the context of corrections, specifically in six state correctional institutes (SCIs) in a Mid-Atlantic State.<sup>19</sup> In the next phase of the project, the collaborative team of researchers and research partners from inside the prison system prioritized needs and developed intervention strategies. These approaches were compiled into the Toolkit for Enhancing EOL Care in Prison and piloted in six SCIs.<sup>18</sup>

The success of the pilot demonstrated proof of concept; however, dissemination was limited due to the

cumbersome format of the Toolkit and the influence of the collaborative partnership between researchers and insiders. The next phase of the project shifted towards the development and testing of media rich, computer-based learning modules for broad dissemination and subsequent evaluation of effectiveness in stimulating change to the care delivery system.

## **Lessons Learned**

Transforming healthcare systems is a change in the culture of care, regardless of the setting or context of that system. Efforts to launch sustainable transformation must be strategic and thoughtful. The lessons learned through this program of research are not limited to prisons; rather, these lessons provide relevant considerations for nurse scientists working to transform healthcare systems in any setting.

## **Understand the System**

Understanding the current care delivery system is essential for planning sustainable transformation. Systems are inherently complex. A stakeholder analysis is a useful tool in the planning phase to determine whose interests or workflow should be taken into account in the planned change. Identify the segments or sectors involved in the current care delivery system and the "players" in each segment of the targeted system. Consider influence and power in each segment to begin to understand how the

system currently functions.

These preliminary considerations can be invaluable in planning change. Powerful stakeholders can be influential change agents or significant barriers to change. Alliances may be established to groom champions who will foster sustained change. Baseline understanding builds your capacity to anticipate challenges or barriers and to proactively plan strategies. While you may think that you understand a system, the stakeholder analysis often reveals nuances that warrant your attention throughout the transformation. Time invested in understanding the system is well-spent and may smooth the process of transformation.

## **It's All About Relationships**

Our work has demonstrated the importance of creating and fostering relationships with key stakeholders in the system. Researchers or change agents are often viewed as disruptive outsiders. Building a strong network of collaborative partners promotes access to the system and sets the stage for developing a shared vision of desired outcomes. We found that involvement of key stakeholders during the conceptualization of the project was critical to crafting a feasible approach that fit the context of the care delivery system. Gaining the support of leadership was only the first step in relationship-building.

Gaining access to the setting promotes entry; however,

access alone is insufficient for understanding the culture of care. Insiders or those who dwell within a given culture hold values and beliefs that are often implicit, not reportable or easily identified. The transformation of care delivery systems requires an in-depth understanding of providers' values and beliefs. Influential stakeholders who exercise formal or informal power may be identified. This understanding helps uncover potential facilitators and barriers to change.

Credibility is established through relationship building. Consider the currency of the system. Academic degrees, professorial rank, and clinical credentials are not highly valued in all systems. In fact, these indicators of status may contribute to the insider-outsider divide. It is essential that preliminary interactions with the system targeted for transformation build open communications that manifest trust. Our team's immersion in the world of corrections was carefully orchestrated to expose usual practices and attitudes. Throughout these interactions with insiders, the staff members inside the system were positioned as our mentors or guides. We asked questions freely to untangle the many acronyms or slang phrases that held unique meaning in this context. Without this baseline understanding, efforts to change this system would have been misguided and ineffective.

## **Transformation Takes Time and Leadership**

Systems are inherently complex and stimulating a

sustainable transformation in care delivery can take time. Most projects are based on a timeline of benchmarks of progress toward goals. The timeline sets expectations of progress, but rarely does a project unfold according to plan. Our team learned to anticipate delays and re-organize our workflow to achieve our goals. For example, approval for the involvement of human subjects is one area that can upset the timeline early in the project. It is not uncommon for participating institutions to require review (if not approval) by an internal review board after the formal review/approval of the project is obtained. This process takes time; in some cases, the internal committee may meet quarterly or cancel meetings unexpectedly. The challenge for the project team is to avoid feeling "dead in the water" during such delays. Our team often used early delay-time to organize and summarize literature for future publications. Later, data cleaning and analysis peaked during delays. The trick is to avoid losing momentum during delays.

As the transformation is planned and implemented, the best estimates of time sometime prove inadequate. At the same time, funded projects have a definite start and end point. The capability to adapt to circumstances and meet objectives is a skill that is learned over time. Experienced, high functioning teams develop the capacity to anticipate challenges or delays and to respond nimbly. Less experienced teams may tend toward frustration or despair when challenges emerge. These situations require

leadership skills to guide the project team through collaborative problem-solving to adapt the plan and meet major objectives. Leadership skills are often tested in transformation projects -- this is not a "one-man" show, leaders must know how to effectively engage a team.

## **Build Awareness of the Need for Change**

Many times, insiders are unaware or unconcerned with the proposed transformation. Insiders often focus on workflow patterns that become accepted routines. Transforming patterns of care is more effective when those involved understand why upsetting their usual routine is desirable. On first blush, one may think that a one-time educational program is adequate to set the stage for change. Rarely is this true.

It is critical to consider options that reach identified stakeholders to build an awareness of the need for system change. In our work in the prisons, we realized how multiple segments of the system influenced care delivery. Our work in end-of-life care was not limited to medical personnel. Security personnel controlled movement of inmates and influenced patterns of care. Counselors and clergy helped inmates interpret the illness trajectory. Volunteers or inmate-workers assisted with care and communicated with other inmates. Administrators could offer special dispensation for cases that were brought to their attention. Building an awareness of need emerged as a significant factor in stimulating change and a one-time

in-service clearly was not the answer. Think carefully to craft your message and disseminate that message strategically to reach all stakeholders involved in the system change.

## **Sustainability Starts in the Conceptualization Phase**

Too often a project leader assumes that all parties will see the wisdom of a planned change and will sustain the desired change over time. Yet, most professionals can cite a “flash in the pan” approach to change. That is, change agents come, they implement the change, and over time, the system reverts to business as usual. Sustainability of change requires careful consideration during project planning and throughout implementation. For example, the initial stakeholder analysis provides some insight regarding potential champions within the system who may monitor and sustain the desired change. Integrating stakeholders into the implementation phase helps to infuse the desired change into current practices most effectively. Grooming champions to promote sustained change is strategic. For example, consider the value of recognition of efforts. We learned that co-authorship of professional publications held little value for most of our partners. Institutional and peer recognition (e.g., newsletter stories) were valued more highly. Knowing these nuances can be very helpful in promoting sustained change.

Sharing results of the system change with all stakeholders builds appreciation of how the change has improved targeted outcomes or quality. We have learned that these communications are best tailored to each stakeholder segment in order to build continued support for the system change. We considered the "what's in it for me?" question to ensure that our approaches and ongoing communications reflected values of importance to each segment of the organization.

## **Final Thoughts**

Nurses have been challenged to transform systems in order to improve quality outcomes. We have been called to step out of our comfort zone to take on new and innovative ways of thinking. This disruption is challenging, uncomfortable. Yet we have learned that following the pathway to innovation can be a very productive and meaningful experience. Expect to maximize your leadership skills as you face new challenges. Remember that transformation of a system often yields transformation of the leader.

## **Works Cited**

<sup>1</sup> Penrod, Janice, Judith E. Hupcey, Brenda L. Baney, and Susan J. Loeb. "End-of-life caregiving trajectories." *Clinical Nursing Research* 20, no. 1 (2011): 7-24.

<sup>2</sup> Penrod, Janice, Brenda Baney, Susan J. Loeb, Gwen

McGhan, and Peggy Z. Shipley. "The influence of the culture of care on informal caregivers' experiences."

*Advances in Nursing Science* 35, no. 1 (2012): 64.

<sup>3</sup> Carson, E. Ann, and Elizabeth Anderson. "Prisoners in 2015." *Bureau of Justice Statistics*, December 2016. [Link](#)

<sup>4</sup> Aday, Ronald, and Azrini Wahidin. "Older Prisoners' Experiences of Death, Dying and Grief Behind Bars." *The Howard Journal of Crime and Justice* 55, no. 3 (2016): 312-327.

<sup>5</sup> Bolano, Marielle, Cyrus Ahalt, Christine Ritchie, Irena Stijacic-Cenzer, and Brie Williams. "Detained and Distressed: Persistent Distressing Symptoms in a Population of Older Jail Inmates." *Journal of the American Geriatrics Society* 64, no. 11 (2016): 2349-2355.

<sup>6</sup> Counsell, Steven R., Christopher M. Callahan, Daniel O. Clark, Wanzhu Tu, Amna B. Buttar, Timothy E. Stump, and Gretchen D. Ricketts. "Geriatric care management for low-income seniors: a randomized controlled trial." *Journal of the American Medical Association* 298, no. 22 (2007): 2623-2633.

<sup>7</sup> Williams, Brie A., James S. Goodwin, Jacques Baillargeon, Cyrus Ahalt, and Louise C. Walter. "Addressing the aging crisis in US criminal justice health care." *Journal of the American Geriatrics Society* 60, no. 6 (2012): 1150-1156.

<sup>8</sup> U.S Department of Justice. "The Impact of an Aging Inmate Population on the Federal Bureau of Prisons" last modified February 2016. [Link](#)

<sup>9</sup> Carson, E. Ann, and William J. Sabol. *Aging of the State Prison Population, 1993-2013*. US Department of Justice, Office of Justice Programs, Bureau of Justice Statistics, 2016.

<sup>10</sup> Aday, Ron H. *Aging prisoners: Crisis in American corrections*. Penn State Press, 2003.

<sup>11</sup> Kerbs, John J., and Jennifer M. Jolley. "A commentary on age segregation for older prisoners: Philosophical and pragmatic considerations for correctional systems." *Criminal Justice Review* 34, no. 1 (2009): 119-139.

<sup>12</sup> Williams, Brie A., Karla Lindquist, Rebecca L. Sudore, Heidi M. Strupp, Donna J. Willmott, and Louise C. Walter. "Being old and doing time: Functional impairment and adverse experiences of geriatric female prisoners." *Journal of the American Geriatrics Society* 54, no. 4 (2006): 702-707.

<sup>13</sup> The Pew Charitable Trust. "State prison health care spending: An examination." Retrieved November 13, 2014.

<sup>14</sup> Binswanger, Ingrid A., Patrick M. Krueger, and John F. Steiner. "Prevalence of chronic medical conditions among jail and prison inmates in the United States compared with

the general population." *Journal of Epidemiology & Community Health* (2009): jech-2009.

<sup>15</sup> Maruschak, Laura M., Marcus Berzofsky, and Jennifer Unangst. *Medical problems of state and federal prisoners and jail inmates, 2011-12*. Washington, DC: US Department of Justice, Office of Justice Programs, Bureau of Justice Statistics, 2015.

<sup>16</sup> Williams, Brie A., Jacques G. Baillargeon, Karla Lindquist, Louise C. Walter, Kenneth E. Covinsky, Heather E. Whitson, and Michael A. Steinman. "Medication prescribing practices for older prisoners in the Texas prison system." *American Journal of Public Health* 100, no. 4 (2010): 756-761.

<sup>17</sup> Penrod, Janice, Susan J. Loeb, and Carol A. Smith. "Administrators' Perspectives on Changing Practice in End-of-Life Care in a State Prison System." *Public Health Nursing* 31, no. 2 (2014): 99-108.

<sup>18</sup> Penrod, Janice, Susan J. Loeb, Robert A. Ladonne, and Lea M. Martin. "Empowering Change Agents in Hierarchical Organizations: Participatory Action Research in Prisons." *Research in Nursing & Health* 39, no. 3 (2016): 142-153.

<sup>19</sup> Koch, Tina, and Debbie Kralik. *Participatory Action Research in Health Care*. John Wiley & Sons, 2009.

**Author Bios:**

**Dr. Janice Penrod** is a nurse-researcher whose program of research evolved from studying end-of-life care to examining the transformation of end-of-life care delivery in the prison settings. In addition, Dr. Penrod has expertise in community engaged research, leadership, and building coalitions to promote system change.

**Dr. Kitt-Lewis** is nurse-researcher collaborating on the continued development and testing of media rich, computer-based learning modules for broad dissemination in corrections settings. In addition, Dr. Kitt-Lewis studies linguistic patterns to discern caregivers' ascribed meaning in varied end-of-life caregiving situations.