

August 2016

Rediscovery of Self-Care for Incarcerated Persons with Diabetes

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Recommended Citation

Reagan, Louise; Shelton, Deborah; and Anderson, Elizabeth (2016) "Rediscovery of Self-Care for Incarcerated Persons with Diabetes," *Journal for Evidence-based Practice in Correctional Health*: Vol. 1 : Iss. 1 , Article 5.

Available at: <https://opencommons.uconn.edu/jepch/vol1/iss1/5>

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Abstract

Purpose: To examine self-care for diabetes in the incarcerated population within the framework of the Rediscovery of Self-Care (RSC), a newly developed care model for persons with incarceration experience

Organizing Construct: Diabetes is a chronic illness that requires the development and use complex self-care management skills. The RSC is a strengths-based model promoting the belief that inmate- patients are capable of re-discovering their own strengths for self-care.

Findings: Persons with an incarceration experience have person and environment exposures that reduce their self-care capabilities for diabetes. Using a clinical case management approach, clinicians can assist incarcerated persons with re-entry and re-integration into the community by decreasing vulnerabilities and promoting adaptation, self direction, and the re-discovery of self-care for diabetes.

Conclusions: Incarcerated persons with diabetes have numerous multilevel challenges to engage in diabetes self-care resulting in risk for poor health outcomes while in prison and upon re-entry into the community. Clinicians using the RSC can improve diabetes-related and re-entry outcomes for incarcerated persons.

Clinical Relevance: Theory-based approaches for guiding nursing practice and research in the area of self-care management for this vulnerable population are lacking.

Key words: Inmates, incarceration, self-care, diabetes, self-management

Funding

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Acknowledgements

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Abstract

Purpose: Theory-based approaches for guiding nursing practice and research in the area of self-care management for incarcerated persons is lacking. To address this gap, this paper examines each phase of the Rediscovery of Self-care (RSC) model and uses findings regarding diabetes from the literature and research targeting incarcerated persons with diabetes presented as an applied clinical case study.

Organizing Construct: Diabetes is a chronic illness that requires the development and use of complex self-care management skills. For individuals in prison or jail - the likelihood for self-care management can be a struggle. RSC, a strengths-based model, promotes the belief that incarcerated persons are capable of re-discovering their own strengths and engage in self-care.

Implications/Conclusions: Incarcerated persons with diabetes have numerous multilevel challenges to engage in diabetes self-care resulting in risk for poor health outcomes while in prison and upon re-entry into the community. Clinicians can use RSC to understand the context, processes and outcomes associated with self-care management of diabetes for incarcerated persons. A clinical case management approach can assist incarcerated persons with re-entry and re-integration into the community by decreasing vulnerabilities and promoting adaptation, self-direction, and the re-discovery of self-care for diabetes.

Key words: Inmates, incarceration, self-care, diabetes, self-management

Background

Diabetes occurs in the prison population at similar or slightly greater prevalence than in the community-dwelling prevalence of 4.8% (Binswanger, Kreuger, & Steiner, 2009; Wilper et al., 2009) and is predicted to rise (ADA, 2014). Engaging in self-care behavior (SCB) for diabetes is integral to achieving good glycemic control and reducing the incidence of complications (ADA, 2016; Haas et al., 2013; Norris, Engelgau, & Narayan, 2001).

Diabetes self-management education and support helps persons with diabetes initiate and maintain important SCB and improve disease outcomes (ADA, 2016; Norris, Engelgau, & Narayan, 2001), although challenges are acknowledged in providing care to incarcerated individuals (ADA, 2014). There is little evidence as to what constitutes effective diabetes self-management education (DSME) in the correctional setting. What is known regarding effective DSME has been demonstrated in community samples (Brunisholz, 2014; Powers et al., 2015; Norris et al., 2001). The AADE 7 self-care behaviors of healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks provide a framework for topics to be included in DSME (AADE, 2014; Powers et al, 2015; Tomky et al, 2008) but to our knowledge have not been used thus far to inform DSME in the correctional setting.

Incarcerated persons with diabetes have numerous external and internal barriers that differ from those experienced by persons living with diabetes in the community. These barriers include stringent prison rules for safety and security, inmates' co-existing mental illness and addiction disorders, socioeconomic disadvantage, having English as a second language, and low levels of literacy and health literacy. These external and internal barriers have the potential to complicate the delivery of diabetes self-management education and engagement of incarcerated persons in diabetes self-care.

Nonetheless, persons entering or reentering the correctional system do so with a certain set of skills, even if some skills, such as those related to their criminal activity are misdirected. The RSC (Shelton, Barta, & Anderson, 2016a, 2016b), a developing care model for persons with an incarceration experience, is a strengths-based model which assumes that incarcerated persons are capable of re-discovering their own strengths and apply them to self-care. The RSC provides an excellent framework for enhancing preexisting skills. This paper examines the application of this model to incarcerated persons with diabetes.

Shelton's et al. (2016b, 2016c) model can be applied to any aspect of self-care. However, it generally refers to self-care as a holistic process that leads to problem-solving and goal-oriented behavior for the inmates during times of transition, such as entering prison or reintegrating into society. Along the incarceration experience, the inmate would need to develop and/or adapt self-care to be prepared to manage his or

her health during or after incarceration. Promoting and maintaining diabetes SCBs, including achieving good glycemic control, would be only one component of an inmate's rediscovery of self-care.

Rediscovery of Self-Care (RSC) Model- Revisited

As reflected in figure 1, RSC (see Shelton et al., 2016c *this issue*), grounded in Orem's definition of self-care and concepts from Richardson's (2002) metatheory of resilience, provides a framework guiding clinicians to assess, intervene, and evaluate inmates in all phases of their incarceration experience. Shelton et al. (2016c) view self-care as an action directed by individuals toward themselves or their environments for the purposes of regulating their own functioning and sustaining life under their changing environmental conditions (transition into, through, and out of prison). Further, actions designed to maintain or bring about a condition of well-being are also targeted goals. Richardson's (2002) conceptualization of resilience as a capacity that everyone possesses and a motivator in times of disruptive events is beneficial to achieving adaptation and reintegration into the community following incarceration. Shelton et al. (2016a, 2016b, 2016c) identify resilience-related factors of self-efficacy, motivation, perceived control, and the ability for planning or being able to select and choose self-care activities as critical. Persons entering, living in, or exiting prison may experience a disruption in the ability to engage in self-care. Nurses using the RSC model would seek to increase self-care by increasing resilience-related factors and

reversing or preventing the deskilling and infantilizing that takes place in persons as a result of incarceration experience.

Shelton et al. (2016a, 2016b, 2016c) identified psychosocial, demographic, and individual factors (e.g., mental health, personality, marginalization, hypervigilance, motivation), as well as personal transitions through non-binding stages (vulnerabilities, adaptation, self-direction, and self-care) and environments (community, prison, initial re-entry, and re-entry/re-integration) that may impede or enhance an inmate's ability to develop and maintain self-care. In earlier work, Shelton et al. (2016a) examined stress and vulnerabilities of persons with an incarceration experience. She notes that historic and repeated stressors among persons with a personality disorder and burdened by vulnerabilities (such as prenatal risk, cognitive limitations, disorganized and poor communities, PTSD, and childhood abuse) enhance maladaptive behaviors. Poor outcomes for self-care management, taken broadly, include a range of biological, psychological, social, and criminal outcomes.

Furthermore, Shelton et al. (2016c) provided interventions for care and coordination (e.g., assessments, provision of support, and treatment referrals) necessary to assist the inmates with transitions through the phases—vulnerabilities, adaptation, self-direction and self-care. The RSC, bidirectional and dynamic, takes into account that at any given time during the incarceration experience, persons may flux between the phases of vulnerabilities, adaptation, self-direction, and self-care. Clinicians adjust

interventions for clinical care and case management coordination based upon the strengths and needs of the individual, the setting/environment, and situation.

The next section presents a review and discussion of each phase of the RSC model and utilizes evidence-based findings regarding diabetes from the literature and research conducted by the author targeting incarcerated persons with diabetes (Reagan, Walsh, & Shelton, 2016) presented as an applied clinical case study.

Phase 1: Vulnerabilities

The focus for the first phase of the model is acknowledgment that incarceration is a disruptive life event known to be associated with multiple stressors and threats to self-care (Haney, 2002; World Health Organization [WHO] & International Association for Suicide Prevention [IASP], 2007). During times of transition, clinicians have the opportunity to assess the self-care skills and capabilities of the incarcerated person.

Shelton et al. (2016a, 2016b) classified vulnerability factors related to the person and environment that could positively or negatively affect the incarcerated person's ability to engage in self-care at each phase of the incarceration experience. Person-related factors described as being related to life history include: life circumstances, past medical and psychiatric history, personality, and vocational or interpersonal skills. Environment-related factors are described as: community factors including socioeconomic status (dis)advantage, victimization, and marginalization. The clinical assessment and case management process will increase clinician understanding of the

inmate's current level of vulnerability—the sum total of factors known to increase or decrease the resilience-related factors of perceived control, motivation, self-efficacy, and planning for self-care and help to identify case management needs and promote coping behaviors.

Application to diabetes: To maintain good diabetes control and health, persons with diabetes must engage in many SCBs. Self-care for diabetes includes healthy eating, being physically active, self-monitoring of blood glucose (SMBG), medication taking, problem solving, and reducing risk including smoking cessation, attending annual eye and foot exams and sustaining motivation and healthy coping skills (AADE, 2014). Persons with an incarceration experience may be performing all of these or none of these self-care behaviors depending on where they are on the continuum of the incarceration experience. Transitioning from the community to prison, an incarcerated person may feel a sense of relief that his healthcare and medications are provided, or on the contrary may experience loss of control over not being able to manage diabetes on his/her own terms (Condon et al., 2007). For example, a person who has never been incarcerated and has good support systems, intact cognitive functioning, a job, and health insurance prior to incarceration and suddenly loses the ability to perform self-care may perceive this shift in self-care as a significant stressor and, according to the RSC, a threat to his or her perceived control. Upon assessment, clinicians identify these pre-incarceration strengths and plan with the patient to maintain or encourage self-care

skills appropriate to the prison environment, thereby maximizing preexisting SCBs and re-engaging or adapting the use of SCBs to the current situation.

Co-occurring disorders, which are common among this population, contribute an added burden to the already high rates of chronic diseases such as cardiovascular disease (Arries & Maposa, 2013), diabetes, hepatitis (Herbert, Plugge, Foster, & Doll, 2012), compounded by lower socioeconomic status (Borysova, Mitchell, Sultan, & Williams, 2012). Additionally, as many as one in seven prisoners have mental illness (Fazel & Danesh, 2002) and co-occurring mental health or substance abuse disorders (Fazel & Baillargeon, 2011; Woods, Lanza, Dyson & Gordon, 2013). The combined effects of life history and pre-incarceration environment have the potential to affect perceived control, motivation, and self-efficacy for diabetes self-care and the ability to plan for and engage in self-care. These vulnerabilities can occur at any stage of the model but are more likely to be evidenced during transition phases such as entering incarceration, changing facilities, or being ill prepared for re-entry.

Phase 2: Adaptation

The focus of this phase is on helping incarcerated persons adapt to prison while maintaining or re-discovering and adapting self-care skills. Vulnerability factors identified in Phase 1 and cognitive function will influence how the person responds and adapts to the stress of incarceration and to other changes in usual self-care regimens.

Of importance is the evaluation of the inmate's cognitive function, as memory and executive function are adversely affected by chronic stress (Cavanaugh, Frank, & Allen, 2010) and impact adjustment to the prison environment. Many inmates have chronic stress from pre-incarceration issues such as substance abuse (Binswanger et al, 2012; Calcaterra, Beaty, Mueller, Min, & Binswanger, 2014), untreated or serious mental illness, chronic health conditions (Wilper et al., 2009), prior physical abuse, intimate partner violence, and/or repeated incarceration (Haney, 2002).

The prison environment and the effects of institutionalization, often referred to as "prisonization," when used in the context of inmates are person and environment factors affecting the inmate's identification and perception of stressors and their ability to use available support systems in or outside the prison (Shelton, 2010a, 2010b). Some inmates respond to the highly controlled prison environment and inmate culture by exhibiting signs of withdrawal, dependency, and hyper vigilant behaviors (Haney, 2001; Shelton, 2010a). Inmates with certain types of personality characteristics or a mental health issue may have distorted perception and overestimate the extent of the stressor and, as a result, experience a decline in self-care behaviors and overuse of maladaptive coping strategies (Shelton et al, 2016a; Connor-Smith & Flachsbart, 2007).

Application to diabetes: For incarcerated persons with diabetes, adapting to the prison may mean changing their insulin regime, having insulin administered to them rather than self-administering, curtailing physical activity, or eating unfamiliar foods.

Given the significant constraints to self-care for diabetes in prison, incarceration may negatively affect a person's ability to adapt to new regimes of diabetes self-care and result in increased stress.

Alternatively, during this phase, inmates may benefit from growth-promoting aspects of confinement. Given the close quarters of most jail and prison cells, inmates can benefit from having social support that is greater than what was experienced in the community. A story communicated by an inmate participating in the evaluation of a prison Group Medical Appointment (GMA) that supported a growth-promoting aspect of prison (Reagan, 2011) is worth reflecting upon. This inmate who had English as a second language (ESL) recalled that early in his incarceration and prior to being diagnosed with diabetes, he "was sweating and urinating a lot." He stated that he did not recognize that these symptoms were associated with diabetes. He did not perceive the symptoms as problematic. However, when another inmate told him that he should "get checked for diabetes", he immediately went to the prison medical unit at which point he was diagnosed with diabetes. The social support provided by one inmate and accepted by another inmate illustrates the growth-promoting aspect of prison. When examining the interpersonal relationships of inmates, Wulf-Ludden (2013) found that male and female inmates reported not only having friendships in prison but also that other inmates helped them make improvements in areas of their life.

While assisting an inmate to navigate the healthcare system and identify necessary diabetes self-care behaviors, clinicians should engage with inmates to determine strengths and abilities for engaging in permissible setting-specific levels of diabetes self-care, and subsequently identify and clarify goals for improving self-care for diabetes. These goals should be realistic given the inmates' stressors—e.g. new to insulin, fear, lack of social support, lack of knowledge, and vulnerabilities (health literacy, physical, mental and addiction disorders, etc). As soon as the inmate's behavior has stabilized, and they are considered to have adapted to the prison setting, re-entry preparation should begin.

Phase 3: Self-Direction

This phase establishes a strong foundation for successful transition or re-entry into the community. Because self-care is a holistic process, clinicians assist inmates with self-care related to many areas such as securing housing and accessing health care programs. Although this paper focuses on the processes related to diabetes, techniques that increase goal setting, problem solving, and emotion control are applicable to other diseases and aspects of self-care. As an example, cognitive behavioral therapy (CBT), motivational interviewing, and Wellness Recovery Action Planning (WRAP) (Cook et al., 2011; Cook et al, 2013) have been found to be effective for self-care management of mental illness and substance abuse issues. CBT has been found effective for improving

adherence to medication, depressive symptoms, and glycemic control (Safren et al., 2014).

Application to diabetes: Inmates are prepared for other transitions, such as transferring between facilities within the prison system to a unit with a lower level of security and where they may gain some new privileges such as more unstructured time, time for outside recreation or the ability to keep approved medications in his or her cell. However, if the inmate is not self-directed to seek solutions to problems that arise as a result of this transition (transfer), he or she could experience a decline in self-care for diabetes and in other areas of his or her life where self-care is required. To illustrate this phenomenon, one inmate reported that he used to check the blood glucose at another facility. However, after transfer to the current facility, he indicated that he was no longer called down to medical to have his blood glucose checked (Reagan et al, 2016). The inmate made no effort to ask the medical staff about the reason for the change in the plan of care; he thought that this was the predetermined plan of care at the new facility.

Using the constructs of the RSC to examine this inmate's behavior, the transfer to the new prison, in this case a transition and a disruptive event, resulted in a decline in the inmate's perceived control and ability to secure resources and thus plan for continued diabetes self-care. The inmate identified that there was a change in an aspect of his diabetes care but did not appraise this as a problem or identify the change in

routine as a cue to seek solutions. Multiple factors such as cognitive or emotional vulnerabilities of the inmate, lack of social support in a new environment, or system issues due to poor nursing and team communication with the inmate and other facilities could have influenced this situation.

For inmates with diabetes, having the ability to identify the signs and symptoms of hypo/hyperglycemia (situation awareness) is a life-sustaining self-care skill. Essential components of this skill include having knowledge of the signs and symptoms and an awareness of the personal cues that signify a high or low blood sugar. In a study examining the relationship of diabetes knowledge, self-care behavior, and illness representations with respect to glycemic control, Reagan et al. (2016) found that out of 124 inmates, only 60.5% identified the signs and symptoms of hypoglycemia and 61.3% identified the signs and symptoms of hyperglycemia. Having insufficient knowledge about hypo- and hyperglycemia is a barrier for developing self-care management for this problem. If the signs and symptoms are not readily attributed to a problem with the diabetes, the inmate will not be able to set appropriate goals and develop strategies for problem solving such as going to the medical clinic or checking the blood glucose.

Some prisons do not allow inmates to have access to a glucometer. Inmates with this restriction might have difficulty with timely validation of symptoms and setting goals to manage these symptoms. Until recently, access to glucometers was not allowed in most state correctional environments in the U.S. Preliminary findings from a quality

improvement project in a U.S. prison support that having keep on person (KOP) glucometers for selected inmates enhanced self-care and improved health outcomes (Ball, 2011; Reagan et al, 2016). Allowing inmates access to glucometers would give nurses opportunities to work with inmates on developing and practicing skills for self-management of blood glucose monitoring (SMBG) and self-direction prior to re-entry.

Additionally, there is some evidence of less restrictive glucometer and insulin policies at the international level. Condon et al. (2007) noted that most inmates surveyed were allowed access to glucometers for SMBG and administered their own insulin under the observation of a nurse ($N = 111$). Even with less restrictive policies, the inmate participants of this study perceived that prison rules dictated health care policies and decreased their autonomy to engage in healthcare (Condon et al., 2007). This finding may suggest that inmates wish to be more involved in their diabetes care. This study did not address safety issues or problems associated with inmates performing these SCBs.

Phase 4: Self-Care

Oftentimes, the clinician role in helping incarcerated persons to rediscover self-care is not easy. Nurses, typically experts at developing nurse-patient relationships, have to balance the concerns of custody and caring when assisting inmates through the phases of the RSC. Assisting inmates toward self-care and preparation for release can be easily visualized through execution of the education role of nurses.

Application to diabetes. For example, Reagan et al. (2016) found that greater than 50% of inmates ($N = 124$) surveyed did not know the normal value for the Hemoglobin A1C (A1C). However, greater than 80% of inmates ($N = 124$) surveyed by Reagan et al. (2016) identified complications associated with diabetes. It is possible that incarcerated persons participating in this study had poor understanding of the association between poor glycemic control and high A1C and the development of specific complications. Nurses can help incarcerated persons with diabetes understand the importance of maintaining A1C less than 7% to decrease their morbidity and mortality and use this information as a motivator to reach an A1C of less than 7%. Following this knowledge, nurses can teach inmates how to set goals for lowering or maintaining A1C and to problem solve when the A1C is high or worsening.

Assisting inmates to visualize situations that they will be confronted with, and decisions they will need to make related to diabetes, as well as other aspects of self-care can assist them with their re-entry to the community. Shelton et al (2010a, 2010b) found that the use of structured workbooks to assist inmates in their thought processes was an effective strategy both within and outside the prison.

Recommendations for Practice and Research

Self-care management of chronic diseases, such as diabetes, is essential for successful re-entry into the community. It has been suggested that incarcerated persons with chronic illness transitioning to the community are at risk for substance abuse

relapse and reincarceration (Binswanger et al., 2012). Yet, fewer research and quality improvement initiatives have been conducted to improve chronic illness or diabetes care in the prison or with recently incarcerated individuals. Effective interventions to enhance factors antecedent to diabetes SCB such as self-efficacy, goal setting, coping, and problem solving are abundant in the literature. Interventions are often multifaceted and have been examined in diverse community-dwelling participants who have one or more chronic illnesses. Many of these interventions have been found to enhance skills for diabetes self-care (Newlin Lew, Nowlin, Chyun & Melkus, 2014; Norris, Engelgau, & Narayan, 2001) should be appropriately modified to account for the context of prison and the effect of incarceration and tested in the prison setting (Reagan & Shelton, 2015).

Being mindful of the distinctive set of psychological adaptations that often occurs in response to the demands of prison life involves the incorporation of the norms of prison life into incarcerated person's habits of thinking, feeling, and acting. As a result, adaptations may include behaviors that challenge support of self-care behaviors, such as the relinquishment of autonomy; interpersonal mistrust and suspicion; social withdrawal and isolation; and diminished sense of self-worth and personal value. These prisonization effects jeopardize the positive personal and behavioral coping adaptations required for self-care and successful transition from prison and reintegration into society.

The RSC is an easily applied model that accounts for dynamic movement of the inmate through various phases and environments of the incarceration experience. Because it is common for inmates as patients to have multiple conditions that require self-care management, researchers and clinicians could use the RSC model to organize interventions and care for multiple chronic physical and mental health conditions. Some of these constructs or themes have already been examined in non-incarcerated populations. Reflecting on the review of the literature and suggested interventions noted elsewhere in this issue (Shelton et al, 2016) might be helpful for determining the direction for future research on self-care for the incarcerated population and guide the development of tailored interventions to improve diabetes self-care.

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