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Humanbecoming Paradigms to the Experiences of Individuals
Living with Spinal Cord Injury**

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Justice, Health & Disability:
Applying Justice and Humanbecoming Paradigms to the
Experiences of Individuals Living with Spinal Cord Injury

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Justice, Health & Disability:
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The conceptual metaparadigms of nursing theory include; person, nursing, health, & environment. Social justice appears as a side note, perhaps assumed to fall under the umbrella of environment, with the caveat that some have argued for its inclusion stating that social justice acts as the practical concept that runs through and connects the other metaparadigm concepts (McEwin, 2019). Even Though the American Nurses Association includes social justice within provision 9 of its Code of Ethics (ANA) and there is a long history of social activism within the nursing profession; social justice still lacks emphasis among nursing theories and within undergraduate nursing curriculums that have become increasing focused on simply equipping graduates to be able to pass the NCLEX (Reichlin, et al., 2018).

Part of incorporating a social justice mindset into nursing practice involves critically analyzing the social context our patients live in and identifying systemic injustices that negatively impact their well-being (Reichlin, et al., 2018). One issue where I think a social justice nursing theory could be applied is in maintaining continuity of care for persons living with spinal cord injury.

Living with Spinal Cord Injury

Persons living with spinal cord injury face a very specific set of challenges in their daily lives and often lack sufficient social support when they are out in the community (Alexander, 2020). Living with spinal cord injury is expensive (Furlan, et al., 2017), even those with good health insurance coverage often face financial hardship (Barzallo, 2018). Clear corroboration has

been shown to exist between the socio-economic environment a person living with spinal cord injury is in and their health outcomes (Alve & Bontje, 2019). A poorly maintained sidewalk is only a minor inconvenience for a person with no mobility issues, but for a quadriplegic dependent on a power wheelchair it can become an insurmountable obstacle. Even if a person living with spinal cord injury can get to see a primary provider, most community primary providers are not sufficiently familiar with spinal cord injury to provide adequate care. This lack of understanding of spinal cord injuries is often exacerbated other biases carried by medical personnel working in lower income communities (Kuemmel, et al., 2020).

The daily challenges of impaired mobility coupled with latent prejudice in society resulting in insufficient accommodation and further exacerbated by frustrations with the quality of medical care in the community can lead to higher instances of anxiety and depression among people living with spinal cord injury (Myaskovsky, et al., 2017). Often these challenges result in persons living with spinal cord injury having no feasible choice for living accommodations outside of skilled nursing facilities which typically do not have sufficient staff to accommodate the burden of care for persons living with spinal cord injury. The staff they do have often lack an adequate understanding of the specific needs of persons living with spinal cord injury (Razaei, et al., 2019). To achieve successful health and functional outcomes to maintain acceptable quality of life persons living with spinal cord injury require an effective network of interactive interdisciplinary relationships spanning the inpatient clinical team, community medical team, caregivers, and the person living with spinal cord injury. Absent this sophisticated level of care the peculiar specifics of spinal cord injury along with the multiple secondary complications

and comorbidities among persons living with spinal cord injury, their prospects are grim at best (Gibson-Gill, et al., 2020).

The barriers faced by persons living with spinal cord injury are social justice issues because many of the inequalities are a product of society that has not encouraged equity across social groups. Delivery of lower quality primary care, lack of accommodations for environmental barriers, and inadequate living facilities should be deemed unacceptable. Nurses are ideally positioned to act as agents of social justice because of their unique relationships with persons living with spinal cord injury (Kuemmel, et al., 2020).

Case Example

John was a veteran of the Korean war who sustained an incomplete spinal cord injury. While he maintained some very limited upper body function, he was dependent for all care and activities of daily living. He often found himself admitted to the inpatient unit to get over a respiratory infection or recover from a pressure ulcer wound. John was well acquainted with the staff on the inpatient unit and was very satisfied with the care he received there. Before too long John would be healed up and discharged to the nursing home where he lived. The nursing home was not really staffed to accommodate residents living with spinal cord injury and so John was severely limited in which activities of daily living he could realistically accomplish on any given day. Often, the over worked staff would not be able to take the time to dress John and get him set up in his power chair, so many days of his life were spent lying in bed watching reruns on TV. Before long, John would develop another pressure ulcer or get sick with a respiratory infection and be transferred back to the inpatient spinal cord injury unit at the Veteran's Hospital to get healed up again. This pattern of frequent readmission for repeat infections and pressure ulcers continued for many years until John eventually succumbed to a bout with pneumonia.

While the Veterans Administration did provide John with weekly home care visits by a spinal cord injury specialized nurse, more frequent visits were not felt to be justified since John lived in a skilled nursing facility, despite his pattern of frequent inpatient readmissions. Obviously, John was not receiving the care and support he needed to maintain his health and provide him with an adequate sense of well-being. But, to ameliorate the disparities that contributed to John's poor outcomes would require interventions to confront the systemic issues John faced (Kuemmel, et al., 2020) as well as a care plan that could be implemented in the community tailored to his specific medical, psychosocial, cultural, and socioeconomic needs (Myaskovsky, et al., 2017). Hence the need for the application of a nursing theory of social justice.

The Road Forward

Mitigating the challenges faced by persons living with spinal cord injury requires a holistic approach that can hold in balance and simultaneously address multiple facets that impinge upon an individual's well-being. To do so successfully, one needs to maintain a view of the "lights on the horizon" through an understanding of the grand nursing theories at play and then drill down to the specific steps and actions required to achieve meaningful well-being in any given situation.

Theoretical Framework

Nursing care for, and living with, spinal cord injury can be a very task oriented profession. It is important for nurses to keep our orientation on the grander view of well-being; seeing the health of individual patients we care for in the context of the whole of their lives, relationships, and connections beyond the immediacy of the present disease (Hitzig, et al., 2019). Additionally, it is important to utilize a more holistic paradigm that

views individual health as intrinsically connected to community well-being. People living with spinal cord injury are acutely aware that injury and sickness are often fundamental aspects in the rhythm of life, and we should recognize that we increasingly dwell in “disabled” landscapes, environments, and systems. We need to move forward in a manner that acknowledges our interdependence of all our relations with each other, the environment, and other species we live with to realize ways of well-being for all persons at all stages of life and abilities (Taylor, 2020).

For persons living with spinal cord injury chronic isolation is a real danger due to the limitations of mobility caused by their conditions. This can develop into a situation where a person’s social interactions are limited to those providing care which can lead to an unhealthy state where the individual’s identity becomes defined by their injury (Chen, 2010). To avoid this situation it is vital to ensure that individuals living with spinal cord injury have the know-how, equipment, and social support to not only have access to appropriate care, but also engage in meaningful social activities (Kuemmel, et al., 2020). Moreover, social justice initiatives must be supported that ensure the social environment and communities that individuals living with spinal cord injury inhabit are safe, supportive, and accessible to enable them to develop positive interactions and relationship to realize healthy states of being (Myaskovsky, et al., 2017). Rosemarie Rizzo Parse’s Humanbecoming Theory provides a paradigm through which the confluence of these clinical, personal, and societal factors can be interacted with in a means that moves us towards actualizing healthy well-being (Wills, 2019).

On Humanbecoming

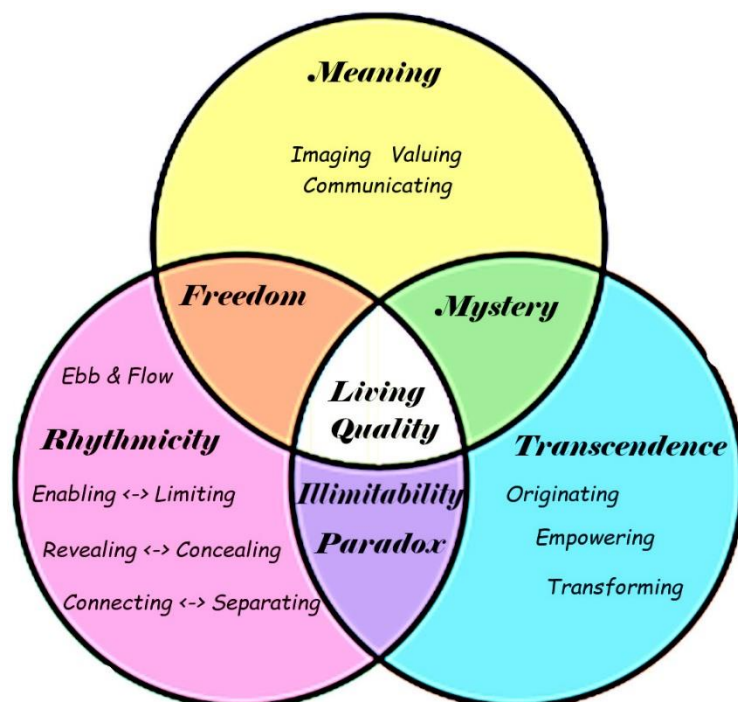
Parse’s grand theory seeks to empower nurses to guide individuals and families to define their own health process that will enhance their quality of life within the context of their community perspective. Rather than necessitating individual behavioral change, the

humanbecoming paradigm explores ways to contextualize medical priorities into the cultural understanding of well-being that the individual already values (ICPS, n.d.). Moving in this way of being is understood through three themes; meaning, rhythmicity, & transcendence, and four postulates; freedom, mystery, illimitabilty, & paradox (Parse, 2014). When successfully applied, these act to realizing a phenomenon that Parse refers to as ‘living quality’ (Parse, 2103). While there have been many comprehensive and complex diagrams developed to illustrate The Humanbecoming Theory, for the purposes of this application visualizing the theory in a more streamlined Venn diagram seems most appropriate.

Parse has a penchant for originating creative word constructs and phrasings to free us from our preconceived notions of conceptual knowledge and move our thinking away from static designations and into dynamic behaviors of understanding (Parse, 2013). Hence humanbecoming instead of self-actualization, rhythmicity instead of rhythm of life, living quality instead of quality of life, etc. When considering applications of the

themes and postulates of The Humanbecoming Theory, it is important to maintain the dynamic perspective for crafting interventions that will enable transformative meaning (Chen, 2010).

Defining the Themes of Humanbecoming



Meaning. This is an ongoing process of empathy and understanding. In building rapport with the patient the nurse should work to create a safe space for the patient to articulate their values and how those values are manifested in their choices and actions (Parse, 2014). Spinal cord injury is a drastic life altering event, often activities that had provided a sense of meaning for an individual are no longer possible. After spinal cord injury a person is much more dependent on the help of others which can severely impact one's sense of autonomy and worth. Individuals with spinal cord injury often lose their previous means of financial stability while simultaneously facing extreme financial burden from clinical expenses, home modifications, and adaptive equipment (Gibson-Gill, et al., 2020). Nurses working with individuals living with spinal cord injury not only need to create space for a patient to express their values, but also must work with the patient in establishing new ideas and approaches to experience meaning through their drastically altered realities after spinal cord injury (Chen, 2010).

Rhythmicity. This is the aligning of one's intentions with the natural ebb & flow of the universe. Rather than resisting undesirable experiences, one learns to flow with them in the inevitable undulation of experiences. This releases the individual from an insistence on exerting control and frees them to more fully experience the positive aspects existence (Parse, 2014). The individual living with spinal cord injury is acutely aware that the notion of control is ultimately a false construct. Nurses should work with these patients to discover their naturally occurring rhythms of being and establish routines that fit clinical needs and considerations into that natural rhythm (Hitzig, et al., 2019). Activities of daily living that are often simple and mundane for mobility typical individuals can be time consuming and challenging endeavors for those living with spinal cord injury. Careful planning and thorough understanding of a patient's natural rhythms are required to accomplish these needful tasks (Rezaei, et al., 2019). Successful

rhythmicity with activities of daily living frees the patient from being consumed by tasks so that they will have time and energy to pursue endeavors that bring them meaning.

Transcendence. This is the process of ongoing discovery of the emerging possibilities present in every moment and experience (ICPS, n.d.). It is about simultaneously holding one's values, what has been important, one's experiences, what is important right now, and one's possibilities, what will be important moving forward, in dynamic balance to fully realize "living quality" (Parse, 2013). Moving in transcendence enables the patient in maintaining connection to the values that provide a sense of well-being regardless of the stressors that the current moment holds (Parse, 2014).

Transcendence is especially poignant for the person living with spinal cord injury as their moments are often fraught with challenges that can become emotionally draining and lead to despair and depression (Hitzig, et al., 2019). Establishing a practice of transcendence provides a pathway out of the tyranny of the moment to connect with a greater sense of well-being.

The Four Postulates. Parse defines four postulates; freedom, mystery, illimitability, & paradox, that permeate the three themes (Parse, 2014). These postulates can be conceived as different lenses through which to view the themes as the current situation warrants. For this reason they are placed in the areas of confluence of the themes in the Venn diagram. These postulates provide the perspective to conceive the themes as ways of knowing that empower one to fully realize living quality. Far beyond merely a satisfying quality of life, Parse envisions living quality as a state of being where one's personal story intersects the deeper meaning of all our relations and connections in a dynamic experience of knowing (Parse, 2013).

Humanbecoming to Living Quality

Parse's concept of living quality and paradigm of humanbecoming offer a fairly unique perspective among grand nursing theories in that rather than trying to fix a problem, its emphasis is on developing new conceptions of understanding to make sense of our situations and empower the patient to develop a perspective that brings meaning to their state of being (Petiprin, 2020). This approach is especially poignant for individuals living with spinal cord injury as they often face a host of issues that are unfixable (Hitzig, et al., 2019). The Humanbecoming Theory offers a paradigm that can enable and empower persons living with spinal cord injury to rise above their daily challenges and realize a living quality that provides an enduring sense of meaning and purpose.

Restoration: Beyond Social Justice

Rosemarie Rizzo Parse details in her Humanbecoming Theory a confluence of personal, societal, and clinical factors that are dynamically interactive. The nurse is in a critical position to influence these interactions in a manner that can help the individual, and by extension their family, community, and society, actualize healthy well-being (Wills, 2019). Approaching social justice from a Humanbecoming paradigm brings one to a place where simply fighting to correct social determinants of health is only a first step. How do we move from preventing actual harm to healing the harm that was caused? This brings us to the realm of restorative justice; which I believe is the natural confluence of social justice and humanbecoming.

In North America, restorative justice began as a concept developed primarily in Mennonite communities exploring ways to apply their understandings of the teachings of Jesus to the justice system (Zehr, 1990). The foundational concept of restorative justice is that rather than focusing on the punishment of the offender, healing of wounds caused by the offense is the

primary objective (Zehr, 2015). As the restorative justice movement grew it realized that the fundamental concepts it was developing were already established traditions in many Indigenous communities; most notably among the Maori of New Zealand (Braithwaite, 1989), and the Ojibway of Canada (Ross, 1996). Since restorative justice is focused on healing it makes a natural fit for nursing which is also a discipline focused on healing.

Restorative justice practice has over 40 years of research showing that it promotes significantly reduced rates of offender recidivism as well as increased victim satisfaction with the justice process. Beyond individual crimes there are societal injustices and cross cultural violence whose harms manifest across generations that restorative justice practice can help to heal (Umbreit & Armour, 2011). The holistic theory of integral nursing holds that achieving health and wellness implies engagement in social action and sacred activism (Dossey, 2016). There are many parallels between the best practice techniques for physical healing and the best practice techniques for social/community healing. The restorative concept provides a framework that can bind these concepts together in a practice that provides health and well-being (Drucker, 2014).

Practical Application

Put succinctly, restorative justice is a theory that emphasizes healing harm through a cooperative process involving all stakeholders that leads to transformation of communities, relationships, and people. This process was originally envisioned through three themes of harms/needs, obligations, and engagement; but has since been expanded to four pillars: Inclusion of all parties, encountering the other side, making amends for the harm, reintegration of the parties (Zehr, 2015). Replacing the criminology lens with a

healthcare lens we can see these ideas as: Interdisciplinary collaboration, patient-centered paradigm, finding pathways towards healing, living in a true state of well-being – or living quality (Parse, 2013). We can explore each of these ideas by applying them to our case example and imagine how a restorative justice approach to humanbecoming may have influenced the outcomes.

Interdisciplinary Collaboration

Including all parties in the conversation when crafting care plans is not a new or especially groundbreaking idea. But, while there is much talk about interdisciplinary collaboration, how often it is actually applied and practiced is a whole other matter. The clinical nurse leader is ideally positioned to ensure that appropriate communication and collaboration takes place (Bender, et al., 2012). Obviously, this collaboration would include hospital inpatient clinical staff, outpatient services, skilled nursing facility staff, and other care caregivers; but to be truly effective should also include social workers, community contacts, family, and, most importantly, the patient (Chen, 2010).

For John, the patient from the case example, facilitating active collaboration between all of the stakeholders would have provided for better continuity of care between the hospital and nursing home environment. Additionally, it would have given John's social worker the information to justify more comprehensive care from outpatient services since the documentation showing the nursing home wasn't fully equipped or staffed for the needs of a spinal cord injury patient would have been readily available (Kuemmel, et al., 2020). Furthermore, the humanbecoming paradigm would have revealed that John was falling short of the potential quality of life he desired, while the restorative justice framework would seek to repair the cause

of that limiting harm and so provided the impetus to advocate for legislation to address the chronic understaffing of the skilled nursing facility where John lived (PNHP, 2021).

Patient-Centered Paradigm

In restorative justice “encountering the other side” grew out of the overlap of the themes of obligations and engagement (Zehr, 2015). A healthcare framework realizes this as the medical providers intentionally encountering the personality, culture, and preferences of the patient. Patient centeredness is particularly critical for individuals living with spinal cord injury as primary providers are often ill informed about the peculiar needs of spinal cord injury patients (Kuemmel, et al., 2020). This makes empowering patient self-advocacy critically important to ensure consistency and continuity of care (Rezaei, et al., 2019). The ascendancy of the individual through honored self-advocacy draws together the themes of humanbecoming into authentic living quality (Parse, 2013).

A patient centered paradigm would have empowered John to better direct his own care while living in the skilled nursing facility as well as defining with the over worked staff his care priorities, so while they couldn't provide all the care he needed they would have been sure to provide what mattered most to John. Additionally, patient-centered care could have enhanced more timely communication to outpatient services so they could have leveraged their specialized spinal cord injury training to more quickly intervene when issues arose before they became critical enough to require an inpatient hospital stay. Moreover, continuity of care would be improved since all the medical providers involved in John's care would have understood, and ideally advocated for, his priorities for what defined health and well-being.

Pathways Toward Healing

Healing harms can be conceptualized as restoring what was lost (Ross, 1996). In the context of humanbecoming this necessitates drawing focus back from the individual interactions between nurse and patient and putting our efforts toward addressing the systemic and structural issues creating the disparities that are driving the harm (Reichlin, et al., 2018). To facilitate restoration that leads to healthy living quality, interventions to address systemic disparities as well as individual care must be crafted in a manner that builds self esteem and autonomy while targeting specific needs (Myaskovsky, et al., 2017). This process has the potential to highlight our mutual vulnerability and that our response to individual sickness or disability is inherently a societal issue encompassing our symbiosis with the health of the entire ecosystem (Taylor, 2020). Seen in this light it becomes clear that pathways towards healing is a road we must all walk together. Coming alongside patients in our shared journey toward living quality, rather than clinging to hierarchies that create demeaning paternalistic relationships, is the best practice to realize the best outcomes (Kuemmel, et al., 2020).

In the last years of his life John had developed a fatalistic attitude that grew from the powerlessness he felt over his destiny. Rather than enjoying the time he had left, he was despondently waiting for the end. A restorative justice application of humanbecoming would have helped prevent the onset that despondency by replacing John's sense of merely being a burden to others with a rich camaraderie with those who were on the path with him and just happened to also be providing his care. This would have also served to enhance communication as regular communication between John and those providing his care would have become the norm. Thus John's needs and desires would have been readily understood by his care team

enabling them to craft a care plan that created a path toward healing and a state of well-being that held value for John.

Living Quality

The term “quality of life” has a static character to it as if it is merely a commodity to be acquired. Living quality better embodies the dynamic state of living in true well-being (Parse, 2013). In restorative justice reintegration is where restoration is truly realized. While most think of the perpetrator when considering reintegration, it is typically the victim who has suffered the most intense isolation as theirs incorporates both a physical and psychological component (Zehr, 2015). Individuals are always changed by their experiences, so there is never going back to how things were as if nothing had ever happened; but restorative justice seeks a path through healing for the best that can be (Braithwaite, 1989). In a health care perspective, for an individual with a new spinal cord injury this could be coming to terms with their “new normal” (Alve & Bontje, 2019). For someone who has lived with a spinal cord injury for many years, like John, this could be restoring trust in his relationships with caregivers and clinical staff whom he felt let him down (Hitzig, et al., 2019).

If a restorative justice application of humanbecoming had been employed by the individuals involved in John’s care there would have been recognition of the lost hope John experienced in his final years and a more active effort to identify the factors that could have helped restore John’s sense of value, meaning and purpose. Identification of and accommodation for the activities and interactions that truly brought John joy could have been provided for. Rather than spending his final years simply waiting for the end to come, John could have enjoyed life to its fullest possible potential had a restorative

justice application of humanbecoming been an active part of his care plan. This would have allowed John to truly experience living quality up to his final heartbeat.

Summary

Living with spinal cord injury is incredibly challenging and offers particular obstacles not often experienced with other chronic conditions making individuals living with spinal cord injury often dependent on some level of help from others. This requires specialized adaptive skills and attention to peculiar abnormalities that are often not well understood by those an individual living with spinal cord injury interacts with socially nor by primary care providers in the community where these individuals often reside. Likewise, medical professionals who specialize in caring for individuals living with spinal cord injury must develop specific and adaptable medical understanding that is tailored to each individual patient the medical professional works with. For this reason, a person living with spinal cord injury often develops long term professional relationships with spinal cord injury specialized medical staff. However, these specialized medical professionals who know the patient well are often not the ones the individual living with spinal cord injury interacts with on a daily basis. This requires the person living with spinal cord injury to be a competent and confident self-advocate capable of directing their care needs with whomever is providing their care in the moment. I believe this dynamic makes a restorative justice approach to humanbecoming especially poignant to individuals living with spinal cord injury.

Social justice advocacy becomes inherent for individuals living with spinal cord injury and the medical professionals who specialize in their care to ensure that adequate accommodations are in place to overcome the barriers to care and activities of daily living experienced by individuals living with spinal cord injury. But this advocacy only address the

very base level of needs experienced by this community. The evolution from social justice to restorative justice is a natural occurrence when the theory of humanbecoming is applied to this people group. The status-quo indicators of meaning, value, and success are often acquired through activities no longer possible for individuals living with spinal cord injury. But rather than hold these individuals as disabled, humanbecoming theory declares the societal definitions of meaning, value, and success are the thing that is invalid. Humanbecoming theory empowers individuals living with spinal cord injury to define their own standards of meaning, rhythmicity, and transcendence; while application of restorative justice theory provides the pathway fully live into meaning, rhythmicity, and transcendence to realize authentic living quality.

While that may seem grandiose and esoteric to some; the realization of restorative justice requires hard work, determination, and grit. But all of this advocacy comes to nothing if it is not done with a deep sense of care and compassion, and that is what nurses specialize in most of all.

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