Lessons for spinal cord injury rehabilitation taken from adult developmental psychology: 2011 Essie Morgan Lecture

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Background/objective: Developmental phases affect how individuals cope with and challenge threats to self-concept, health and functioning. Understanding prominent models of adult psychological development can help spinal cord injury/disease (SCI/D) rehabilitation professionals facilitate positive change and growth.

Design: Author's theoretical model informed by literature review and personal experience.

Setting: Veterans administration (VA) medical center interdisciplinary outpatient clinic providing primary and specialty care to veterans with spinal cord injuries and disorders.

Conclusion: Threats to life expectations, health, well-being, identity, and other aspects of self create crises that can result in psychopathology or psychological growth. SCI/D can present multiple threats across the lifespan. For example, self-image, ability to perform various activities, ability to feel attractive, and even life itself may be challenged by SCI/D or its complications. Threats may be perceived at the time of injury or onset of symptoms. Also, as the injured body declines further over time, complications can cause significant temporary or permanent functional decline. Individuals interpret each of these threats in the context of current developmental needs. How people cope is influenced by developmental factors and personality traits. An integrated model of adult psychological development based on the works of Erikson, Gutmann, and Baltes is related to the literature on coping with SCI/D. This model provides insights that interdisciplinary rehabilitation teams may use to facilitate personal growth, optimal functioning, and physical health as adults with SCI negotiate normal developmental challenges throughout their lifetimes.

Keywords: Disability, Aging, Mental health, Life satisfaction, Personality development, Unconscious, Spinal cord injuries, Rehabilitation, Adaptation, Psychological, Patient care team, Life change events, Sense of coherence

Introduction

Threats to life expectations, health, well-being, identity, and other aspects of self create crises that can result in psychopathology or post-traumatic growth. For people who survive, spinal cord injury/disease (SCI/D) involves progressive physical decline. First, there is an acceleration of normal physical aging. Increases in the rate of aging of organ systems have been described, and are associated with early development of conditions such as diabetes mellitus and cardiovascular disease.¹ These can further complicate and exacerbate the effects of SCI/D. Aging with disability is also associated with long-term overuse of parts of the body needed for mobility, leading to symptoms such as shoulder deterioration, postural problems, and the increased likelihood

of other medical conditions due to the disability itself, such as osteoporosis. Secondary complications such as pressure sores and urinary tract infections are common, and sometimes serious enough to require prolonged periods of bed rest, which in turn may lead to other complications.

Aging with (or without) a disability occurs in the context of multiple losses including the deaths of friends and family, empty nest and retirement, and physiological and mental slowing. Remarkably, most elderly people around the globe regard old age as a more satisfying time of life than middle age, until they reach a time of terminal illness and decline.²

Happiness and mental health tend to improve with age, particularly after children become independent.³ While most studies concur that perceived stress declines with advanced age and life satisfaction improves, the

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latter finding is inconsistent, particularly in longitudinal studies.⁴ Research indicates that poor satisfaction with life predicts depression in people with SCI/D, but improvements in both are correlated with time since injury, for both SCI and multiple sclerosis. However, that may be a cohort effect of cross-sectional research designs.⁵ In a 22-year study of 1927 male veterans, Mrozcek and Shapiro⁴ found that life satisfaction as measured by the ISI-A steadily improved starting at age 40, then gradually declined after age 65, apart from a sharp decline in the year before death. Furthermore, personality variables were the best predictors of the rates of change. Extroversion was associated with slower rates of improvement and later decline in life satisfaction. Veterans scoring low in extroversion reported less life satisfaction at 40, and improved more rapidly than extroverts, but never caught up. After age 65 their life-satisfaction declined more rapidly than that of their more extroverted peers. Men who were higher in 'neuroticism' reported lower levels of life satisfaction across their adult lifespan, with no correlated difference in rates of change. Health and marriage were positively correlated with life satisfaction, but not associated with rates of change. In the most complex analysis of aging with a spinal cord injury that I have seen, Weitzenkamp *et al.*⁶ followed 315 patients who had been injured at least 9 years, for 10 years. Combining cross-sectional and longitudinal methods for three times of measurement, they found that:

'Frequently, outcomes changed longitudinally without showing any cross-sectional differences. Cross-sectional age was more commonly associated with the worsening of a condition while cross-sectional YPI [years post injury] was commonly associated with improvement. After controlling for cross-sectional effects, psychological measures generally showed minor deterioration, measures of community integration both improved and deteriorated ...' (p.301).

Charlifue *et al.*⁷ and Bombardier *et al.*⁵ also found cross-sectional and longitudinal designs resulted in markedly different outcomes for people aging with SCI.

Kathryn Yorkston⁸ observed that many researchers attribute the decline in perceived stress and improved well-being to learning to ignore or minimize negative emotions and focusing one's energy toward more emotionally meaningful goals. Similarly, 'many adults with serious, long-term disabilities report a good or an excellent quality of life, despite obvious limitations in physical function.' (p. 1698). For instance, Kemp *et al.*⁹ found that post-polio syndrome by itself does

not relate to higher depression scores or lower life satisfaction for older adults. Using three times of measurement, Krause and Broderick's¹⁰ 30-year longitudinal study of the natural course of aging after spinal cord injury found people with SCI reported diminished satisfaction with health and social activity over time, but also an increase in self-reported adjustment over time. Interestingly, participants were asked to predict their level of adjustment 5 years in the future. At each time of measurement, participants predicted their adjustment would be worse in five years, even though ratings of the present consistently *improved* over time.

By order of Congress, the Veterans Administration asks all veterans to have a comprehensive interdisciplinary check-up each year. In their annual evaluations, I ask patients to rate their health and mood. I have observed that commonly, mood and life satisfaction do suffer concurrently with functional decline, but patients adapt and return to prior levels of life satisfaction within two years. This is consistent with research showing that both age and time since injury (or new symptoms) are associated with life satisfaction.^{8,11} Yorkston's⁸ study showed adjustments to disability such as learning to pace one's self (budgeting energy), learning one's limits, using recommended prosthetics and accepting care from others took years. I have observed that a minority of patients emerge from this process stronger and developmentally advanced, while a smaller minority develop chronic mental illness. Consistent with this, McMillen and Cook¹² found that 78% of patients with SCI eventually experienced post-traumatic growth.

Age appears to be a mediator in the process of self-evaluation following SCI/D. Bombardier *et al.*⁵ conclude that the literature indicates post-traumatic growth is more likely at younger age. They posit that older adults may have some expectation of physical decline that diminishes the trauma of becoming disabled. Consistent with developmental theory, they believe SCI/D may pose a greater challenge to personal integrity for younger adults than older. I would add that at least for older men, the need to accommodate to negative life events is consistent with the momentum of their psychological development. For example:

An older professional I treated worked long hours. Because of his drinking problem and infidelity, his wife left him. Late one night, he tripped on his cat; as a result of the fall he had C4 ASIA B ventilator-dependent tetraplegia with chronic pain. After a year in rehabilitation he was able to wean from his ventilator. He was appreciative of all the help he received and regretted how he had treated people. He realized that although he was paralyzed, he could still do a lot for others. He made

amends with his wife; they remained divorced, but she assumed primary responsibility for his care until he was settled. He took a more responsible role in mentoring his adult children. He joined two service organizations and rose to positions of leadership. He understood the impact of the choices he'd made, the limits of his insight at the time, and his future potential. He developed wisdom and the ability to care for the next generation. This is post-traumatic growth.

My own work in the Department of Veterans Affairs is predominantly with men. The literature indicates that aging with an SCI/D is more difficult for women. A review by McColl¹³ found:

'The co-incidence of three risk factors (age, gender and disability) results in an excess of depression among older women with spinal cord injuries

The literature raises three social issues for older disabled women, including caregiving issues, employment/finances and transportation. Higher rates of divorce, separation, and remaining single among women with disabilities mean that they are more likely than men to receive personal care from an attendant.' [p 371.]

Pentland *et al.*¹⁴ add that due to women's greater longevity and the other factors cited by McColl,¹³ older women with SCI report more isolation, dependency, and financial worries than men.

Adult development is particularly complex because humans become increasingly diverse with age. The varied and sometimes contradictory research findings regarding the course of aging with SCI/D point to the importance of understanding the uniqueness of each individual. Many factors come together to determine which of our patients will thrive and who will be defeated by the challenges of SCI/D. Certainly, proper medical care, physical therapy, occupational therapy, recreational therapy, vocational rehabilitation, nursing care, sufficient family, friend and community resources facilitated by social work, and direct and indirect interventions by psychologists – the joint efforts of disciplines represented by the Academy of SCI Professionals and others, make a major impact on outcomes. Additionally, interaction between the patients' own developmental strengths and vulnerabilities, and the meaning that specific disabilities hold for individuals, influences readiness to accept our interventions and the ability to realize their own potential following injury or disease. Understanding adult psychological development can help SCI professionals tailor

interventions so they will be most likely to have a positive impact on outcomes for specific patients.

There are several theories to explain and predict various aspects of adult development. I will briefly review my own integration of theories developed by Erikson, Gutmann and Baltes – three that I have found most useful in working with older people with disabilities.

Erik Erikson¹⁵ identified eight psychological conflicts that people experience in all cultures (Table 1). Because we are generally unaware that we are working to resolve these, they are referred to as unconscious conflicts. Societies support individuals through these internal growth struggles at particular ages that vary a bit from one culture to the next. Thus, according to Neugarten, a conflict may be 'on time' or 'off time'.¹⁶ The conflicts are usually sequential, but they are never fully resolved, and people experience 'pre-working' of future conflicts at earlier ages and 're-working' of earlier conflicts at later ages.¹⁷

Many researchers have confirmed a link between successful aging and achieving an acceptable balance in each of the developmental tasks described by Erikson. Fisher³ for example, using an open-ended survey with 40 foster grandparents aged 61–92, found that once basic needs were met, 'interactions with others, a sense of purpose, self-acceptance, personal growth, and autonomy' were key to late-life satisfaction and mental health. Especially strong were findings that generativity contributed to successful aging and remained a vital developmental task in later life, as did learning to live with adversity rather than fighting to overcome it.

Middle-aged adults in our society are typically struggling with the need to put children, mentees or work products first. This often involves being willing to sacrifice their own advancement and care needs in the service of those people or products that will carry their legacy forward. Individuals with SCI/D may experience additional difficulty in this struggle as they simultaneously work to recover or maintain their own

Table 1 Erikson's developmental challenges

USA age	Challenge	Optimal outcome
1. 0–2	Basic trust vs. mistrust	Drive and hope
2. 2–3	Autonomy vs. shame and doubt	Self-control and will
3. 3–5	Initiative vs. guilt	Direction, purpose
4. 7–15	Industry vs. inferiority	Procedural competence
5. 13–22	Identity vs. role confusion	Devotion & fidelity
6. 23–25	Intimacy vs. isolation	Affiliation and love
7. 25–50	Generativity vs. stagnation	Production & care
8. 60–death	Ego integrity vs. despair	Wisdom

Ages adjusted per author's observations of 21st century USA.

physical functioning. Lost money or economic potential due to care needs and unemployment may also compound the picture as the individual with SCI/D makes difficult choices about how to spend limited resources. Thus, physical disability may handicap opportunities for psychological development. Societal factors may exacerbate or ameliorate this obstacle to growth. McColl *et al.*¹⁸ found that Americans with SCI reported greater social integration, fewer psychological problems, more life satisfaction and less perception that they were aging worse than their able-bodied peers, compared to British and Canadians. They attributed this to the effects of the Americans with Disabilities Act on opportunities and on attitudes toward people with SCI. Benefits such as a generous pension, free prosthetics and free medical care enjoyed by U.S. military veterans with service-connected SCI/D probably account for the finding that older SCI veterans report greater life satisfaction than their able-bodied peers.¹⁸

Similarly, an increased need for assistance may stimulate a return of earlier conflicts over identity (as a rugged individualist or a commando, for example) or emotional intimacy (if, for example, the demands of rehabilitation stimulate focus on one's self to the exclusion of empathy with one's partner). Changes in physical capacity can, in fact, be associated with the need to re-work any earlier conflict, especially if the original resolution was inadequate. So, for example, a patient who developed a limited sense of hope may be more vulnerable to suicide after exacerbation of a disabling condition, and less capable of mounting sufficient effort to participate fully in rehabilitation.

The following case study demonstrates these issues: A 68-year-old man with multiple sclerosis tries to deal with feelings of shame left from his early childhood. This manifests as bragging about himself, complaining about how he is treated and wearing flashy clothes. Four years ago, he started using a scooter for distance mobility. Two years later, he began falling more frequently and his clinician and therapist recommended a power wheelchair for indoor mobility. The staff emphasized the advantages—greater safety, increased better maneuverability and personal energy conservation. The patient refused. His trunk muscles weakened further and there was no way to provide proper posture in his scooter. After reviewing his developmental conflict and coping style, I suggested downplaying the functional value of a power wheelchair. Instead, we stressed the modern look of the new power wheelchairs and how users sat taller for better eye contact and more attractive posture. The patient was then willing to accept and use a power chair.

People with SCI/D may form a new identity with disability at its core. Yorkston *et al.*'s⁸ description of focus groups of persons aging with SCI/D found the following.

'Participants identified themselves both with their disability group and the duration of their disability. For example, those with SCI indicated that they were part of the 'first generation' of people with a disability who will 'live to old age' (M: SCI: 52). One participant who lived with SCI for over 35 years called herself, 'the grandmother of spinal cord injuries' (F: SCI: 66). In another example, participants with PPS suggested that they were 'dinosaurs' (F: PPS: 67) and, in what may be, the last generation of people with a history of polio.' (pp. 1700).

People who attain a strong sense of identity prior to SCI/D may be less inclined to identify with their disability or an affinity group.

'If I hadn't broken my neck, I would have gone down not the same road but probably had the same enthusiasm about life' (M:SCI: 48). Several participants with PPS [post-polio syndrome] suggested they had led a full and 'normal' life (pp. 1700).⁸

Huyck and Hoyer¹⁹ said that 'According to Erikson, a woman's primary sense of identity is bound to her need to provide adequate provision for her children. The ability to be yielding and accommodating helps to maintain an intimate relationship with a husband and father.' (pp. 214). Young men, on the other hand, must establish an identity that will lead to activities that can provide for a family and that will also foster a commitment to bring home the resources they are able to obtain.

David Gutmann²⁰ expanded Erikson's theory with his concept of The Parental Imperative. Studying isolated cultures across the globe, Gutmann found that compared to when they are actively raising children, gender differences in accommodation and assertiveness are relatively minimal for pre-parental men and women. Once offspring are successfully launched, women reclaim interest in self-promotion, competitiveness and power, and men reclaim their earlier comfort with sensual, nurturing aspects of themselves. Relative to their parental years, post-parental men value love more and power less, and are more comfortable with their own dependency needs.

It should be noted that these gender typologies have been criticized by others who believe that our gender-linked

behaviors are the result of social forces. Nevertheless, research confirms their existence in modern America.²¹ Civil rights feminists, including Betty Friedan have acknowledged the utility of sexual differentiation in the service of parenting, and celebrated the forces of late-life androgyny that Gutmann calls 'Reclaimed Powers'.²² Gutmann acknowledges that our society is trending away from this normative pattern of development, and observes that individuals who do not repress some opposite sex characteristics at the expected time remain childless, or their children may suffer from the resultant parenting behaviors.

If we apply this understanding of human psychological development to the needs of older adults at varying stages of SCI/D, professionals from all disciplines can tailor interventions for maximum probability of success. For example, an older post-parental man who is perceived to be too passive by his rehabilitation team may respond poorly if told to accept more responsibility for his care. Such instruction goes against his normal developmental inclination to become more accommodating and less assertive. Instead, staff may capitalize on the man's developmental momentum by disclosing desire to understand him better, thereby appealing to his growing desire for intimacy. Encouraging this patient to accommodate to his new level of disability while helping staff observe the process while he participates in rehabilitation activities might appeal to his growing willingness to adapt and his growing desire to help others. Similarly, pairing him with a less experienced rehabilitation patient might appeal to his generativity. Staff should be alert to the greater probability that this sort of older individual is less likely to complain when he is dissatisfied with his care plan. They may need to probe to uncover dissatisfaction in order to create a collaborative plan for optimal outcome. A different approach might work better with a male patient who is childless, or one who still has dependent offspring.

Staff must keep in mind that adults develop at varying rates, and sometimes not in the expected order. Trial and error at matching interventions to a patient's developmental phase can be minimized by developmental assessment in collaboration with the team's rehabilitation psychologist.

Older adults are more likely than younger people to be working toward attainment of a sense of *ego-integrity*. By this term, Erikson¹⁵ referred to the need to accept that the choices one has made in the course of life were inevitable given one's knowledge, skills and abilities at the time. Out of this struggle, one may obtain the sense that life has had meaning. *Wisdom*

comes from the realization that decisions are only good in the context of one's experience and available choices at the time. Alternatively, people may be overwhelmed with thoughts starting with 'If only I had ...' leaving them despaired at missed opportunities that they can never recover. This particular developmental struggle is common at some point when changes in physical functioning are acute. It is part of the expectable process of accepting the permanence of a disability. This is true for age-related disabilities and for disabilities caused by trauma or specific illnesses. However, the struggle is aided by normal social supports when it is experienced at the age when people in the society expect to see it.

Erikson's theory of wisdom was confirmed by the qualitative and empirical research of Paul Baltes, who studied individuals around the world thought to be wise by their society, and ordinary people in his native Germany.

Criteria for Wisdom.²³

1. Rich factual knowledge about life matters
2. Rich procedural knowledge about life problems
3. Relativism
4. Uncertainty: Knowledge about the relative indeterminacy and unpredictability of life and ways to manage
5. Life-span contextualism

Rehabilitation programs are typically good at educating patients in the facts of achieving and maintaining health with SCI/D. They provide opportunity for practice and graduated independence. Patients have ample opportunity to compare their situation to those more and less fortunate (relativism). Life's uncertainty is hammered home by the unexpected experience of disability. Rehabilitation psychologists and others are available to help the patient gain perspective on how current experience fits in the context of their life experience. This is what Janoff-Bulman²³ referred to as existential reevaluation leading to post-traumatic growth. Thus, for the patient who is ready, rehabilitation provides opportunity to enhance wisdom.

Another aspect of life-span contextualism is the importance of attaining a sense of self-continuity after SCI/D. Persons with disabilities need to re-connect with who they were before the disability. This has been a common struggle for patients I have seen. Re-defining what it means to be one's self and deciding that despite outward change they are the same person on the inside is a critical piece of adaptation to injury for most.

Most patients gradually establish self-continuity by identifying what made activities meaningful and

finding new ways to fulfill the same desires and needs. Focusing on function instead of how one gets something done is quite useful. Unfortunately, some patients take a 'part makes the whole' view of life. These individuals refuse to believe that they can fulfill any of their life goals because they have lost some ability. They are likely to be angry and/or depressed, and prone to self-neglect. Such individuals require persistent efforts from the entire rehabilitation team over a long period (often several years) in order to build satisfying and meaningful lives.

'You never knew what was going to happen, after you got used to that, whether it took a year or two or three years, you were that same person again who dealt with that adversity and just continued on.' (67 year-old patient with post-polio syndrome cited by Yorkston,⁸ pp. 1701).

Clinicians benefit from understanding that the same comment may mean something very different to various speakers and listeners. In the veterans administration (VA), we try to see every SCI/D patient at least yearly. One of the things I ask our patients each year is what has been their greatest accomplishment over the year. 'Staying out of the hospital' is not an uncommon response. Given the many challenges of staying healthy despite SCI/D, this is not surprising. However, for some, this response reflects self-perception that they have been *active* (assertive) in maintaining their own health over the year. For others, it reflects the belief that they deserve credit for *following* our recommendations and accommodating to their disability needs.

Cognitive-behavioral theory holds that positive aging after trauma is predicted by one's ability to change core beliefs that are shattered by unexpected disability, and enhanced self-efficacy achieved through survival of trauma (Janoff-Bulman²⁴). Psychodynamic theory holds that the variability in long-term psychological outcomes of disability, and the phenomenon of selective attention observed by cognitive theorists of successful aging are greatly influenced by the individual's developmental journey. For some older adults, SCI/D threatens the normal trajectory of adult psychological development, particularly at the onset of disability and at each occurrence of further significant functional decline. In response, people may experience significant developmental growth as they find ways to adapt to new physical challenges, or they may be overwhelmed and persist in employing coping strategies that failed them in the past, yet are reassuringly familiar. This latter group is unable to risk the uncertainty of trying

something new that could result in additional negative outcomes at a time when they are already suffering.

Conclusion

Working together, interdisciplinary rehabilitation teams can assess which developmental conflict is most salient to their patient at the current time. Rehabilitation interventions can then be tailored to capitalize on the momentum of the patient's developmental press. Rehabilitation and developmental goals can be synchronized. Developmental vulnerabilities can be discussed and interventions can be designed to help the patient feel secure. This approach is likely to minimize resistance, maximize collaboration, and facilitate optimal outcomes.

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About the Essie Morgan Lecture

The Essie Morgan Award honors the contributions of social worker Essie Morgan in advancing the care of people with spinal cord injury. After earning her MSW degree at Atlanta University, Morgan joined the staff of the Veterans Administration (VA) Hospital in Tuskegee, Alabama. There she developed a community placement program for psychiatric patients that served as a model for the VA's psychiatric hospital system. In 1965, Morgan joined the VA's Washington Central

Office, Social Work staff, where she became the Chief of the Community Service Section. In this capacity, she provided national leadership and direction in the out-placement of patients into community care settings. She also served as liaison social worker to the Spinal Cord Injury Service. Morgan was later named first Chief of a newly created program, Socio-Economic Rehabilitation and Staff Development, for the Spinal Cord Injury Service, a program that grew out of her effective work as the liaison social worker.

In recognition of her demonstrated administrative and leadership qualities, the VA Administrator of the Department of Veterans Benefits selected her for the post of Area Field Director, Western Region. She completed her VA career as the Manager of the Washington, DC Regional Office. She was the first black woman to hold these positions.

Among her many awards were the Federal Career Women's Award from the Civil Service Commission, and the Speedy Award from the Paralyzed Veterans of America, an award she prized above all others.

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