

Rapid Research Report: Psychological Impact of Acquiring a Disability

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Background Information

Approximately fifteen percent of the world's population (an estimated 1 billion people) live with disabilities, a number that is steadily increasing due to population growth, medical advances, and the ageing process³. According to the Centers for Disease Control and Prevention (CDC), nearly 26 percent of adults (1 in 4 or 61 million adults) in the U.S. have some type of disability⁴. While some individuals with disabilities have congenital disabilities they have lived with their entire lives, others have acquired disabilities through various means such as traumatic accidents, diagnosis of chronic illnesses, or through other life changing means. A newly acquired disability can significantly alter a person's life, both physically and mentally.

Grief commonly occurs after the loss of a loved one, but it can occur for other life experiences as well. For many, acquiring a disability is accompanied by a grieving period. Grief is not limited to sorrow but can elicit many other intense emotions such as fear, rage, anxiety, discomfort (both mentally and physically), and feelings of alienation⁵. Depression and posttraumatic stress disorder commonly accompany the acquirement of a disability, with many people navigating the loss of some abilities while learning to live with new ones⁶.

For many people who acquire a disability in life, they lose a part of their bodies and/or the functionality of part of their bodies. This may be coupled with the loss of physical comfort, vigor, mobility, spontaneity, the ability to engage in certain activities, particular aspects of their previous lifestyles, privacy, a sense of dignity, a sense of control, a sense of efficacy, a degree of independence, friends, employment opportunities, financial stability, their body image, and their sense of self as a whole⁶. How an individual adjusts to a newly acquired disability is strongly linked to who they were prior to the disability onset, including what social, emotional, and financial resources they have access to⁶. In fact, who a person was prior to acquiring a disability is more closely linked to adjustment than how "severe" the impairment itself is⁶.

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³ <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

⁴ <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#:~:text=61%20million%20adults%20in%20the,have%20some%20type%20of%20disability.>

⁵ <https://www.talkspace.com/blog/acquiring-new-disability-affect-mental-health/>

⁶ <https://www.goodtherapy.org/blog/grieving-acquired-disability/>

Research Questions

What is the psychological impact of acquiring a disability?

How do people who have acquired a disability find resources that are available to them?

Adaptation to Disability

Research shows that most people can adapt to an acquired disability, at least partially⁷. One theory of adaptation originates from a study in the 1970s where both paralyzed accident victims and lottery winners were interviewed⁸. Brickman and colleagues found that after one month to one year of time elapsed, both groups returned to the level of happiness they had before either becoming injured or winning the lottery⁸. This study created a concept known as “hedonic adaptation” or the idea that people have a general baseline level of happiness, which varies from person to person and will return to baseline as they navigate positive and negative experiences in life⁸.

For the most part, there are four stages of adjusting to a new form of disability: shock, denial, anger/depression, and adjustment/acceptance^{9,10}. Shock can last for a few hours or much longer and typically involves a state of numbness (both physical and emotional). The second stage, denial, can last anywhere from three weeks to two months⁹. Denial is a defense mechanism that gives the individual space to gradually introduce the idea of their new circumstances. Denial can become problematic, but only if it begins to interfere with a person’s life, treatment, or rehabilitation efforts. Denial is often followed by anger and/or depression. These feelings of anger and/or depression commonly occur when an individual begins to experience changes in social treatment and status as a result of the disability. An individual may grieve for the changes to their body image, function, loss of future expectations and plans, in addition to feelings of loss for the functions they once had⁹. The stage of adjustment and acceptance does not mean the individual who has acquired a disability now feels happy about their circumstances. During this stage, an individual relinquishes false hope and begins to create a more realistic sense of adaptation to their new life based on their limitations¹⁰. At this point, the individual accepts and acknowledges the permanence of their condition. It is important to note that not everyone experiences each of these stages of grief or transitions from one stage to the other in any particular order. The stages are not linear, rather they are a guide to better understand the process of adaptation to disability.

The grieving process after acquiring a disability is common and, in some ways, an important process during the adjustment period. Individuals should give themselves time to mourn and acknowledge that they have suffered a major loss, not only a component of themselves but some of the plans they had made for the future¹¹. It is important during this time that individuals do not

⁷ <https://theincidentaleconomist.com/wordpress/adaptation-to-disability/>

⁸ Brickman, P., Coates, D., & Janoff-Bulman, R. (1978). Lottery winners and accident victims: Is happiness relative? *Journal of Personality and Social Psychology*, 36(8), 917-927. <https://doi.org/10.1037/0022-3514.36.8.917>

⁹ <https://www.disabled-world.com/disability/social-aspects.php#:~:text=The%20stages%20of%20adjusting%20to,stages%20at%20their%20own%20pace.>

¹⁰ <https://universitylifecafe.k-state.edu/bookshelf/health/medicalissues/adjustingtoadisability.html>

¹¹ <https://www.helpguide.org/articles/healthy-living/living-well-with-a-disability.htm>

try to ignore or suppress their feelings. While it is natural to try to avoid pain, it is difficult to work through grief without feeling pain or learning how to cope. This experience of pain and acquiring coping strategies is most successful without judgment. It is also important for people to understand that they will go through a variety of emotions, which is normal and different for everyone. This experience can be unpredictable and will certainly contain emotional highs and lows, but with time, the lows become less intense, and individuals begin to find their new normal.

Another key component to adjusting to life with a disability is to communicate feelings and experiences to family and friends. Social support is a key element to adjustment and has been associated with well-being among persons with acquired disabilities¹². Not only is social support linked with better mental and physical health but also with improved outcomes following trauma¹³. For example, research has shown that individuals who acquire a spinal cord injury and report greater social support perceive themselves to be better adjusted to their newly acquired disability, experience less emotional distress, have a higher quality of life and life satisfaction, and significantly fewer health problems¹³. Spousal relationships that are intimate, trusting, and confiding relationships are typically the most beneficial forms of support for individuals who have acquired a disability¹³. However, alternative support can also contribute to positive adjustment to disability acquirement. According to Thoits, the most effective support system are individuals who have successfully confronted similar stressful experiences¹⁴. Support from someone with a similar experience best matches emotional and practical needs of the individual, providing positive role modeling and coping strategies¹⁴.

Grieving after acquiring a disability is a healthy element of the process. What can become unhealthy is when individuals focus on the past and continue to ruminate over what was lost or wishing to return to their pre-disability “normal.” Beatrice Wright, a founder and leader in the field of rehabilitation psychology, identified that after an individual acquires a disability, they either learn to cope or succumb to their newfound disability¹⁵. When someone succumbs to their disability, they focus on the negative impact their disability has on their life and give little attention to the challenge for change and meaningful adaptation¹⁵. To them, the only valid answers are prevention and cure¹⁵. Emphasis is on heartache, pain, loss, and what they can no longer do. They view themselves as pitiful and tragic and feel that their once unique personality is lost¹⁵. Individuals who focus on coping, on the other hand, have active roles in their own lives and their community, which helps prevent devastation resulting from their new circumstance¹⁵. This does not mean that these individuals gloss over the difficulties that lie ahead, rather they are able to deal with the complications that arise instead of pretending that they do not exist¹⁵. It is possible to have a happy life, even if one feels their body is “broken” in some way. Dwelling on

¹² Elliott, T. R., Kurylo, M., & Rivera, P. (2002). Positive growth following acquired physical disability. *Handbook of positive psychology*, 687-699.

¹³ Sherman, J. E., DeVinney, D. J., & Sperling, K. B. (2004). Social Support and Adjustment After Spinal Cord Injury: Influence of Past Peer-Mentoring Experiences and Current Live-In Partner. *Rehabilitation psychology*, 49(2), 140-149.

¹⁴ Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next?. *Journal of health and social behavior*, 53-79.

¹⁵ Wright, B. A. (1983). Coping, succumbing, and hoping. In B. A. Wright, *Physical disability - a psychosocial approach* (pp. 193–216). HarperCollins Publishers.

what used to be or activities that used to be easily accomplished can prove problematic. Instead, individuals benefit from focusing on what they can do and that they can benefit from learning as much as possible about their newly acquired disability. Knowing what has happened (and could happen) to one's body and what to expect can help individuals prepare for the future and help individuals adjust more quickly¹¹.

Resources Available for Newly Disabled Individuals

In addition to navigating the emotional rollercoaster that accompanies acquiring a disability, individuals must also research and identify necessary resources available to them. There is a wide range of programs available, both at the local and national level, for individuals who acquire a disability later in life. Some resources individuals may need include, but are not limited to, assistance with housing, taxes, medical bills, or acquiring service and emotional support animals. The U.S. government offers a variety of federal, state, and local housing programs that can assist with finding an affordable place to live, modifying an existing home, or helping develop skills to live independently¹⁶. Individuals can also find information on assistance from the government with medical bills and insurance options as well as acquiring a service animal that is trained to complete tasks for the individual in need¹⁶.

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against individuals with disabilities. Among these provisions, the ADA requires all health care entities to provide full and equal access for people with disabilities (congenital or acquired)¹⁷. Not only does this guarantee access to healthcare services but ensures that individuals who acquire a disability are provided arrangements to depart the hospital (and resources after) as well. Every hospital has its own policy and procedure for discharging patients, which is especially important for people who need ongoing support (e.g., newly acquired disability). For most hospitals, a care coordinator is responsible for assisting patients with their discharge planning. Care coordinators work with social services to assist with any support that is needed, in addition to providing information about the disability; relevant organizations, support groups, or resources; information about entitlement to any benefits; and how to get support and/or equipment, if needed¹⁸. For example, Craig Hospital, a world-renowned, premier center for specialty rehabilitation and research for people with spinal injury and brain injury, “provides transitional services for patients returning to productive community-based activities such as work or school” as part of discharge planning¹⁹. Their focus is on their patients’ goals of being financially and socially independent and providing services such as, but not limited to, work and school readiness assessment; collaboration with employers, school services/disability services, and volunteer resources; job coaching; job development; career planning; and connection with community resources¹⁹. One such resource, the Christopher and Dana Reeve Foundation, offers free resources to individuals living with paralysis, and helps individuals connect through peer mentoring, finding local resources, virtual support groups, and Quality of Life grants²⁰.

¹⁶ <https://www.usa.gov/disability-financial-support>

¹⁷ <https://adata.org/factsheet/health-care-and-ada>

¹⁸ <https://www.nidirect.gov.uk/articles/hospitals-and-people-disabilities>

¹⁹ <https://craighospital.org/services/community-reintegration>

²⁰ <https://www.christopherreeve.org/get-support>

Prior to discharge from the hospital, individuals with a newly acquired disability should contact their primary care provider to provide an update on the nature of their disability. If an individual needs ongoing health and social support, a team (typically comprised of doctors, nurses, social workers, and/or physical/occupational therapists) will conduct a multi-disciplinary assessment¹⁸.

According to David Kaplan, the Chief Professional Officer of the American Counseling Association, although basic medical needs are essential when someone acquires a disability, getting people into counseling is also crucial. Individual counseling can be extremely beneficial, in addition to group counseling. One important component of group counseling is the need for a mixture of newly disabled individuals and others who are learning how to cope, as well as experienced individuals who have gone through the stages of grief and the adjustment period and can offer support and share their experiences⁵.

Rehabilitation counseling is a field of counseling that specifically applies to working with people during this adjustment period. Counselors in the field of rehabilitation work with individuals with disabilities to help them learn their physical limitations, (potentially) re-learn certain skills, develop accommodations as needed, and generally learn how to adjust to life with a disability. Although there are many facets to the field of rehabilitation counseling, the Division of Vocational Rehabilitation is one of the largest disability resources in the country, assisting individuals with a disability who want to work by providing individualized services to allow individuals to reach their employment goals and live independently²¹.

Conclusion

Adjusting to life after acquiring a disability can be an emotionally difficult time. Individuals will experience grief and loss and may struggle with accepting their new life. Working through the stages of grief and learning how to accept the new aspects of their life are important steps in the process of accepting their disability. Finding resources, such as counseling opportunities, care coordination, benefit information, etc., and learning as much as possible about one's disability can help this process greatly. Learning how to focus on future goals and not what was lost will also help individuals move forward and adjust to their new life with a disability.

²¹ <https://dvr.colorado.gov/>