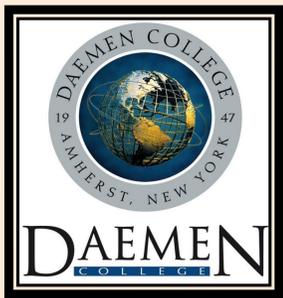# Maintaining Relationships and Identities After a Diagnosis of Illness or Disability

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Purpose

To review the literature in regards to individual's abilities to maintain identities and relationships after the diagnosis of a chronic illness or disease.

Background

Individuals diagnosed with illnesses or disease can express their emotions, social challenges, and relationships that are influenced throughout their life through the use of illness narratives. [1] Chronic illness and disease is prevalent amongst individuals of all ages, ethnicities, and race. Individual's diagnosed with AIDS, CP, Rheumatoid arthritis, stroke, or any other common chronic illness, display common themes which help clinicians and family members to have a better understanding of how the individual perceives their own diagnosis and its impacts on their life.
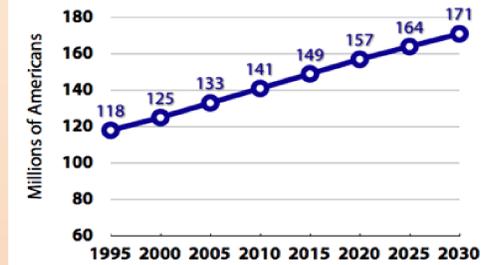
Analysis

Three consistent themes were found amongst the included studies. All studies expressed themes such as the participants' sense of identification, acceptance, and feelings of isolation in relation to chronic illness. For example, both Sanderson et al and Bravemen et al found a common theme of loss of identity[1], or disrupted normality[3] associated with individuals dealing with long-term illness. In regards to feelings of acceptance, Radcliffe et al found that "united couples" who sustained strokes expressed that they were able to adapt to their disabilities together to become self-sufficient; similarly, Sanderson et al found a group of participants who demonstrated a "resetting normality" typology, where normal life includes the individual's illness. Relative to feelings of isolation, all included articles demonstrated similar themes of being distant in relationships and withdrawing from society.

Materials and Methods

Study	Participants	Materials	Methods	Results
. The Narrative of 12 Men with AIDS: Exploring Return to Work By: Brent Braveman, Christine Helfrich, Gary Kielhofner, and Gary Albrecht	❖ 12 Men with a diagnosis of AIDS returning to paid employment ❖ Age range 32 to 52 ❖ Education range from 10th grade to graduate education ❖ 6 of the participants were White, 7 were Black and 3 were Latino	❖ Content analysis was conducted using sections of the text, using the ATLAS (a computer program for qual. analysis) ❖ A panel of 6 individuals were chosen to validate the investigator's interpretation of content from interviews ❖ 2 researches, 2 OTs, and 2 case-workers were included in panel	❖ Narratives were conducted over a 1 year period, 4 separate interview, lasting 60-112 minutes. ❖ Interviews were audiotaped and later transcribed ❖ 1st interview: explored their roles, social contacts, and the environments in which one operates ❖ 2nd, 3rd, 4th interviews: asked about experiences since 1st interview ❖ the conclusion of each interview a narrative slope (did things get better, stay the same, or get worse)	Participants were divided into 3 different groups based on personal experiences. **Progressive Narrative:** 5/12 participants (41%) ❖ Met goals of returning to work & hope for future relationships ❖ Actively engaged in social groups and the community **Stability Narrative:** 34/12 (25%) ❖ Evaluated life as not improving ❖ Avoided discussions about friend or family relationships ❖ Described life as a "roller coaster, with constant highs and lows" **Regressive Narrative:** 4/12(33%) ❖ Furthest from goal of employment ❖ *Decreased sense of identification* ❖ Distant relationships with significant others, "downward spiral"
. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis By: Tessa Sanderson, Michael Calnan, Marianne Morris, Pam Richards, Sarah Hewlett	❖ 23 people living with RA were recruited through a rheumatology outpatient department ❖ Variation was sought across disease duration, global health, age, and gender	❖ Analysis of the interview data was conducted using an analytical tool called Framework:identifying recurring ideas during initial readings of the transcript and tagging them, then identifying links between tags to form themes, and using themes to create a grid in Excel	❖ Participants were interviewed ❖ narrative approach was used ❖ six typologies of normality were developed ❖ classified according to current, dominant typology	❖ **Disrupted normality** – overwhelming symptoms and normal life impossible(2/23) ❖ **Struggling for normality** – presenting a normal life whatever the cost(4/23) ❖ **Resetting normality** – normal life includes my illness(6/23) ❖ **Returning to normality** – normal life reinstated and no symptoms (4/23) ❖ **Continuing normality** – normal life unchallenged (symptoms manageable)(3/23) ❖ **Fluctuating** – life isn't normal when I'm in a flare(4/23)
.Growing Older With Cerebral Palsy: Insider's Perspectives By: Marylyn Horsman, Melinda Suto, Brian Dudgeon, and Susan Harris	❖ 12 participants ❖ Selection criteria included: adults older than 25 who have been diagnosed with CP, had not been diagnosed with any other chronic disability or illness but were experiencing changes in their functional abilities as they got older, had at least a high school diploma, and were able to speak english	❖ Interviews were transcribed and assigned pseudonym ❖ Data analysis involved identifying meaning units, transforming data into specific language, and reducing the data further to convey primary themes. ❖ After the data was divided into units, 48 topics emerged. ❖ The 48 units were organized into clusters of 5 themes that appeared to reflect the data. ❖ After further analysis and discussion, the themes were reduced to 3	❖ The first author gathered data through in-depth semi structured interviews that were audiotaped. Open-ended questions were asked such as what it was like to age with CP, how these experiences were understood, what strategies were used to cope with the changes, and what are the meanings of these experiences. ❖ The other 11 participants were interviewed twice. The first interview was 60-90 minutes and the second one was 45-70 minutes. The second interview allowed the participants to reflect on their experienced and to clarify, validate, and expand upon information provided in the first interview.	This article found 3 common themes among their structured interviews: Awareness, Acceptance, and Action. ❖ Awareness: participants were aware that their bodies were deteriorating quicker than those of their able-bodied peers. These increased physical limitations led to loneliness and isolation from their peers and loved-ones. Most participants believed they would maintain their abilities longer with greater access to therapies. ❖ Acceptance: Participants described coming to a level of acceptance that hasted actions towards improving their quality of life and relationships. All the participants accepted their need to address their difficulties which often resulted in improvements to their everyday life which in the long term would improve their quality of life. ❖ Action: Participants came to understand that their disability was not separate from their personhood, while recognizing that they were more than just their disability. Being able to accept their condition provided these participants with a drive to take action and have a more positive outlook on life.
4. Co-construction of chronic illness narratives by older stroke survivors and their spouses By: Eloise Radcliffe, Karen Lowton, Myfanwy Morgan	- 13 stroke survivors and their spouses - Ages between 75-85 years old	- Interviews were transcribed and assigned pseudonyms. - Interviews were decoded in detail by the content of each stroke survivors narratives. - Veroff et al's (1993) coding scheme was implemented to organize each narrative into either a collaborative style, explicit, implicit, or conflictual style.	- Participants were selected from the South London Stroke Register (SLSR) with stroke participants of all age groups. - Eligibility criteria: participants that have recovered at minimum 1 year post stroke and have a score of seven or above for a mental test score documented on the SLSR. - Interviews ranged between 1 to 2 hours and took place in the participants homes. - Joint interviews began with open ended question that allowed the stroke survivors and their spouses to begin their narrative followed by more detailed narrative questions by the researcher.	Structure of the stroke survivors narratives with their spouses and how they adjusted their role in their lives to respond to their varying levels of responsibility, coping strategies, and disability resulting from the stroke. 1. United Couple 1. Positive Couple 1. Frustrated Couple

Chronic Disease on the Rise

Prevalence of Chronic Disease in the U.S.

Source: Wu, Shin-Yi et al. 2000. Projection of Chronic Illness Prevalence and Cost Inflation. RAND Corporation.

The prevalence of chronic disease continues to rise in the U.S every year, with an estimated 171 million Americans affected in 2030.[5]

Conclusion

Providing a platform for individuals with chronic illnesses to express their story can facilitate individuals in re-defining their identity and their relationships. People suffering from chronic illness commonly withdraw from their loved ones, and isolate themselves from society because they believe others cannot relate to them, and they feel as if their identities have been lost. However, if individuals express their life challenges with others through the use of narratives, they will be able to find alternative coping strategies and find ways to accept their lifelong diagnosis. This will enable individuals to foster healthy relationships with family, friends, and healthcare providers. Further research must be conducted to evaluate the influence of chronic illness and disease on maintaining relationships and identities for a better understanding of what individuals should expect as they age.

References

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