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Reducing Caregiver Burden in Spinal Cord Injuries and Disorders (SCI/D)

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Reducing Caregiver Burden in Spinal Cord Injuries and Disorders (SCI/D)

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Picture of spine model. (n.d.). <https://bit.ly/3bnqo50>

Introduction

- There are approximately 296,000 persons living with SCI/D in the United States (National Spinal Cord Injury Statistical Center, 2021).
- About 80% of people with new injuries are male, and roughly 42,000 people with SCIs are Veterans (Fyffe et al., 2021).
- Overwhelming strain from caregiving responsibilities can ultimately lead to the presence of *caregiver burden*, a term used to describe a level of profound stress that may result in adverse consequences for both the caregiver and receiver of care (Liu et al., 2020).
- The aim of this capstone project was to explore how caregiver education and community resources impact the perception of caregiver burden.

Site Description

- The Department of Veteran Affairs exists as the single largest SCI comprehensive health care providers in the nation with 25 regional SCI/D centers that provide care to 42,000 veterans with SCI/D (Fyffe et al., 2019).
- The site chosen to foster advanced clinical skills was the SCI/D unit at the James A. Haley Veterans Hospital in Tampa, FL.
- Throughout the duration of the 16-week experience, mentorship was provided by two occupational therapists (OTs) who have experience with working with veterans with SCI/D.

Summary of Needs Assessment

Caregiver burden - a phenomenon that can influence the physical, mental, and social functioning of the caregiver's daily life attributable to the large number of duties placed on the person (Conti et al., 2021)

Four identified needs found following the review of current literature included:

- Helping adults with SCI/D find a greater sense of belonging
- Educating the client-caregiver team throughout the transitioning and adjustment process
- Preventing the onset of caregiver burden
- Re-instilling hope through meaningful occupation



James A. Haley Veterans Hospitals and Clinics. (n.d.). VA expansion. <https://bit.ly/3oEIX8B>

Literature Review Summary

Occupational Therapy's Role in Addressing Caregiver Burden

- *The Occupational Therapy Practice Framework: Domain and Process Fourth Edition* considers the client as the individual receiving services and those involved in the care of the client throughout the provision of care (American Occupational Therapy Association [AOTA], 2020).
- The act of caregiving is described as "a co-occupation that requires active participation by both the caregiver and the recipient of care" (AOTA, 2020, p. 9).
- In order to deliver client-centered care to adults with SCI/D who necessitate caretakers for assistance with health management and completion of activities of daily living (ADLs), it is essential that OTs become aware of the distinct needs that exist between the two parties.

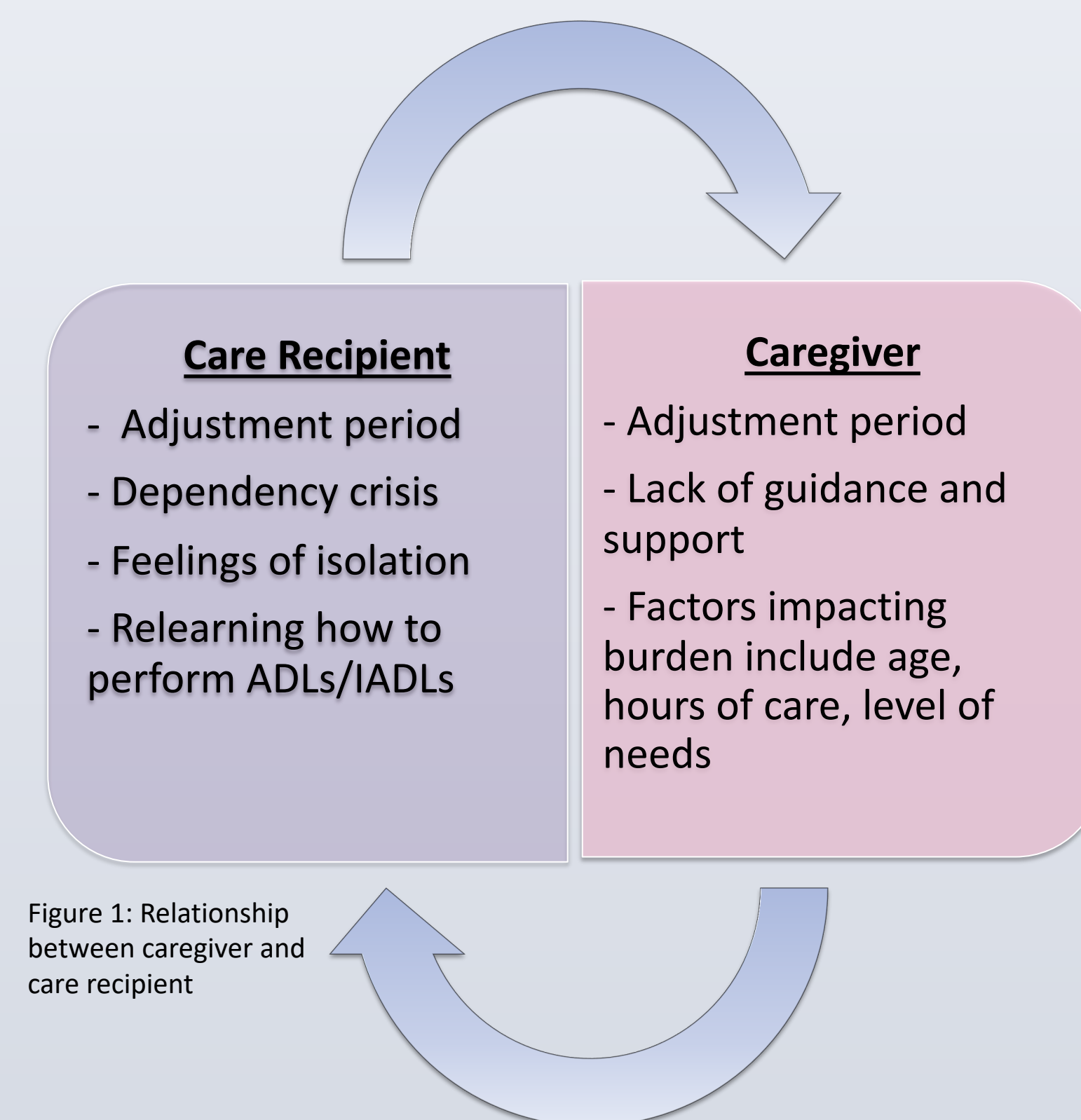


Figure 1: Relationship between caregiver and care recipient

Caregiver Resources

- Caregiver training and health maintenance educational programs have been shown to reduce the cost of care, lower caregiver burden, decrease anxiety and depression, and improve quality of life (Smith et al., 2016).
- One resource provided by the Veteran Health Administration is the Caregiver Support Program (CSP). It is broken down into two programs: The Program of General Caregiver Support Services (PGCSS) and the Program of Comprehensive Assistance for Family Caregivers (PCAFC) (U.S. Dept of Veterans Affairs, 2020).

Type of Support	PGCSS	PCAFC
Caregiver Support Team	✓	✓
Resources for Enhancing All Caregivers Health (REACH) VA	✓	✓
Caregiver Support Line	✓	✓
Caregiver Health & Wellbeing Coaching	✓	✓
Building Better Caregivers	✓	✓
Supportive Services	✓	✓
Caregivers FIRST Skills Training	✓	✓
Peer Support Mentoring	✓	✓
Respite Care	✓	✓
Annie Caregiver Text	✓	✓
Self-care/Resilience courses	✓	✓
Connection to VA/Community Resources	✓	✓
Caregiver & Family Resource Fairs	✓	✓
VA S.A.V.E. Training	✓	✓
Mental Health Counseling (as applicable)	✓	✓
CHAMPVA (if uninsured)		✓
Monthly Stipend		✓
Beneficiary Travel (as applicable)		✓

U.S. Department of Veteran Affairs. (n.d.). Caregiver support program. <https://bit.ly/3OHXntx>

Learning Objectives Achieved

1. The student will demonstrate proficiency in performing all aspects of the occupational therapy process to veterans with SCI/D under supervision of mentoring therapists.
2. The student will increase her understanding of the lived experiences of persons with SCI/D and their caregivers through verbal report and interview.
3. The student will synthesize knowledge from both clinical and professional experiences to create a toolkit that identifies strategies and ideas to reduce caregiver burden.



Sudden Cardiac Arrest Foundation. (2021). <https://bit.ly/3JlSkh>

Implications for OT Practice

- The occupational therapy process should be inclusive towards caregivers to promote optimal success and carryover when clients are discharged from the hospital.
- OTs should collaborate with other disciplines to become knowledgeable of resources and promote utilization of services.
- OTs should play a role in recognizing the need for occupational balance in the caregiver population.
- OTs have an opportunity to provide education to caregivers to mitigate physical and psychosocial challenges that can arise with caregiving.
- OTs should promote independence and prevent learned helplessness to reduce the level of stress placed on caregivers.
- OTs can participate in the delivery of respite care services to provide caregivers with relief from their duties.

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References Available Upon Request

Capstone Project Description

The following capstone project reflected on experiences from an inpatient SCI/D unit for the development of a resource guide that OTs can supply to their clients with SCI/D to empower the client-caregiver team. Resources focused on informing the client and caregiver about all aspects of the diagnosis, promoting mental wellness, providing local resources for support, and describing expectations following discharge.

Contents of Toolkit:

- About this Toolkit
- Conditions of Spinal Cord Injury and Disease
- Returning Home
- Self Care
- Resources
- Useful Handouts



Figure 2: Sample pages from Caregiver Toolkit

