

BEYOND THE DIAGNOSIS: EXPLORING LEISURE EXPERIENCES AMONG NEUROLOGICAL POPULATIONS AND THEIR DOMESTIC PARTNERS

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INTRODUCTION

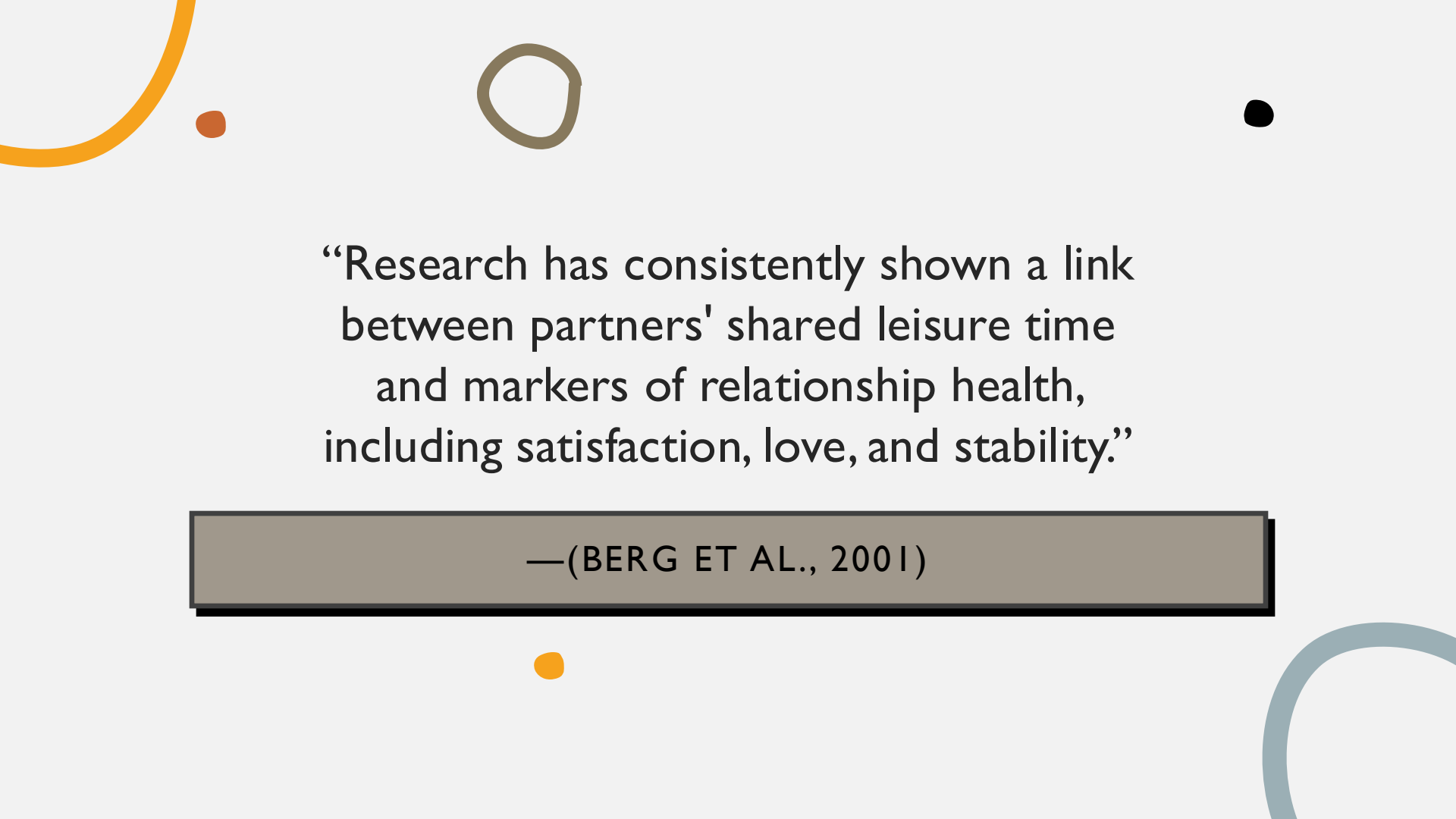
Persons with Neurological Conditions (PwND): Individuals with neurological conditions, such as spinal cord injury, stroke, brain injury, Parkinson's disease, multiple sclerosis, etc. This condition causes symptoms that affect how you move, think and feel (Cleveland Clinic, 2024).

Informal Caregivers: “A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled” (NCI Dictionary, n.d.). They face emotional, physical, and psychological strain, due to the need to balance care responsibilities.

Shared Leisure Experiences: Leisure experiences involving the dyad. It has been studied as a potential tool for improving relationships and well-being (Guerin, 2004), but there is a lack of research in PwND dyads .

BACKGROUND

- Research on disabilities has increasingly begun to focus on improving the quality of life for those with disabilities, as well as their partners.
- “Engagement in shared leisure activities allows caregivers to gain greater satisfaction from their role and perceive it more positively” (Carbonneau et al., 2010).
- Recent studies (Genoe & Dupuis, 2011, 2014) found that “engaging in meaningful activity allowed persons... to cope better with their illness by increasing their sense of control over symptoms and focusing on positive aspects of their lives and remaining abilities.”



“Research has consistently shown a link between partners' shared leisure time and markers of relationship health, including satisfaction, love, and stability.”

—(BERG ET AL., 2001)

RESEARCH OBJECTIVES

- **Explore how caregiver-persons with neurological disabilities (PwND) dyads define and practice shared leisure.**
- **Investigate its impact on relationships and emotional health.**
- **Identify barriers and strategies for meaningful leisure participation.**



METHODS

Participant Enrollment

- **Rolling Enrollment Process:** Participants completed online consent and demographic forms before scheduling interviews.
- **Confidentiality Measures:** Participant names were de-identified and replaced with unique four-character codes.
- **Code Structure:** The first two digits indicate the partnership number (enrollment order), and the last digit identifies the partner's role.
- **Role Designation:** "1" denotes the individual with the neurological condition, and "2" represents their informal caregiver.

PARTICIPANT REQUIREMENTS

Age

Participants must be at least 18 years old at the time of enrollment

Relationship

Participants must be married or in a long-term committed partnership

Condition

Participants must either have a neurological condition or be in a relationship with someone who has a neurological condition.

Comprehension

Participants must have the ability to understand and respond to a 30-minute interview.

INTERVIEW QUESTIONS

1. How many hours a week do you and your partner spend together?
 - a. How much time do you and your partner spend together in leisure?
2. Define leisure for me.
3. What does leisure mean to you?
4. What does leisure mean to you and your partner?
5. When you hear the term shared leisure, what comes to mind?
6. Describe what your shared leisure time and interests are like with your partner.
7. What do you prioritize in planning leisure activities, and what do you feel that partner prioritizes?
8. What do you think may affect your participation in your shared leisure with your partner?
9. What is the effect of your shared leisure participation?
 - a. In general?
 - b. On your relationship?
 - c. On your health and your partner's health?
10. What have you found that helps you when you participate in your shared leisure activities with your partner?

PARTICIPANT STATISTICS

Figure 1. *Demographics of Participants with a Disability*

<u>PwD Demographics</u>	<i>n</i>
Gender	
Female	4
Male	10
Age	
23-27	1
28-32	1
33-37	1
38-42	-
43-47	3
48-52	5
53-57	1
58-62	-
63-67	2
Ethnicity	
White	11
Hispanic/Latino	1
Black/African American	2

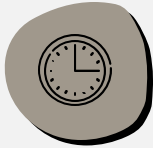
Diagnosis

Amyotrophic Lateral Sclerosis (ALS)	4
Stroke	4
Multiple Sclerosis	4
Traumatic Brain Injury (TBI)	2
Guillain-Barré Syndrome	1
Pompe Disease	1

Length of Relationship

1-5 years	3
5-10 years	2
11-15 years	1
16-20 years	
21-25 years	2
26-30 years	4
31-35 years	1
36-40 years	1

RESULTS: THEMES IDENTIFIED



Leisure is Time Together

- Subthemes:**
- Leisure is Quality Time
 - Leisure is Getting Out



Compromise in Shared Leisure

Participants needed to find flexibility in their partnerships



Reinventing Leisure in the Face of Disability

- Subthemes:**
- Being at the Mercy of the Disability
 - PwND Acknowledging Caregiver Burden
 - Planning Logistics for Successful Leisure
 - Communication
 - Caregiver Education and Expertise

LEISURE IS TIME TOGETHER

0201

Described leisure as “creating memories, creating experiences, creating connections, which is vital in our relationship”

1001

“We don't necessarily have to be doing something fun for it to be leisurely; we can just be... sitting here and I can be doing Legos and she can be like reading something or whatever, and we're spending time together, which is what's important”



LEISURE IS QUALITY TIME

“Since I can't do a lot of those things anymore, you know, I think of [leisure as] more quality time where you're having a conversation, laughing and together.”

-1401



LEISURE IS GETTING OUT

0101

Despite mobility constraints, 0101 highlighted the benefit of simply “getting out in the fresh air... getting out of your living space” to define leisure, adding, “eating outside, doing something different and being able to come back after that, feeling like you’re going somewhere.”

0401

Described the reason that they go out for leisure: “There’s the simple joy of being together. And then there’s the joy of doing new and exciting things. Learning. Seeing.”

COMPROMISE IN SHARED LEISURE

0201

Shared leisure is “ensuring both partners get to enjoy the experience... another side of that give and take... where, um, sometimes it’s prioritizing my leisure... as well as hers”

1401

“Married life is about compromising, as you all have differences, everyone has different interests, and things that they enjoy... we are lucky in that we have a lot of shared interests... but, I mean, we have to compromise a little even though we don’t like it as much because... we’re trying to serve one another”

REINVENTING LEISURE IN THE FACE OF DISABILITY

1301

“We were really trying to re-invent ourselves since the stroke and we're trying to find new ways that we can have that leisure time together.”

0401

“We used to like to bike and be outdoors... now it's more, we go and I'm in the wheelchair and... they tell me about it when they get back. We still do those things. I'm just not a physical participant anymore. I'm kind of just there to be with them.”

BEING AT THE MERCY OF THE DISABILITY

1001

“It’s kind of unpredictable... so it’s hard for us to be like, ‘We’re gonna go do this on Saturday night’ because Saturday and I could come, and I could be like, ‘I cannot get off the couch,’ you know.”

0501

“We... have planned like camping trips and I’ve had to back out because, just too much anxiety.”



PWND ACKNOWLEDGING CAREGIVER BURDEN

0601

“Even though he states that it’s not an inconvenience... I do know that we are not able to... stay at certain events or do certain things as long as we could have done before I got sick.”

1201

“It was very easy to recognize that I was the one that she was gonna try and like favor... if I'm not having a good time, it's probably gonna weigh on her but then also I need to realize that she needs to have a good time as well.”

PLANNING LOGISTICS FOR SUCCESSFUL LEISURE

“I usually always call. People don't call often these days but I call because then I can ask, 'Is this going to be accessible at this time?' You know, 'I'm coming in a wheelchair, do you know anything? Can you prepare for that?’”

-0101

CAREGIVER EXPECTATION AND EDUCATION

1101

“He just joined me for lessons initially just as a caregiver, but he's been doing it for a long time, and I think it's that helped him see a different perspective... I'm seeing him start to, you know, offer a hand when I need to step up a curb or, you know, he's modifying benches to be a little bit taller so that it's easier for me to get up from. Or... adding a foam pad to low chairs... so it just raises it up and makes it less challenging.”

COMMUNICATION

0901

”He knows he knows that I can't do a, b, c, and d, so he often tells me ‘Don't plan too much’... because it'll really affect us later on, so I guess that would be the communication. Have patience to communicate.”

0601

“Try your best to communicate how the way you feel, um, and also be okay that at this moment in time, I feel this way, um, and it's okay for me to let them know, because I feel this way.”

Figuring out leisure after the diagnosis is “finding that new space and the new you, but... continuing to challenge yourself to find something new.”

-0201



DISCUSSION- NEULINGER'S PARADIGM

Neulinger's Paradigm (Webb and Karlis, 2017) offers context for these many different situations and perspectives:

Perceived Freedom Constraints: Caregiving limits the ability to freely choose activities, shifting leisure experiences into structured or responsibility-laden states like *Leisure-work*. PwDs and caregivers often assess whether activities are "worth the time and effort."

Intrinsic Motivation in Balance: Both PwDs and caregivers find intrinsic value in shared experiences, striving for a balance between selflessness and personal enjoyment despite caregiving demands, reflecting a balance of responsibilities.

DISCUSSION CONT.

Fluidity Between Leisure States: Activities often transition between Neulinger's states (e.g., *Pure Leisure* to *Work-job*), as caregiving reframes leisure into externally motivated or constrained tasks while maintaining relational meaning.

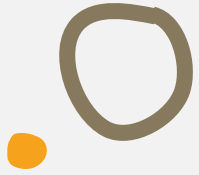
Caregiving as Leisure-work: Caregiving itself often involves intrinsic satisfaction and responsibility, blending the roles of work and leisure as caregivers find purpose despite significant restrictions on freedom.

CONCLUSION

- **Shared Leisure as a Bonding Tool:** Despite challenges like caregiver burden and accessibility limitations, shared leisure fosters relationship bonding, emotional well-being, and mutual joy through creativity, resilience, and empathy.
- **Role of Recreational Therapy:** Therapists can enhance shared leisure experiences by incorporating the dyad into programming, adapting activities to diverse needs, and addressing barriers such as limited resources and autonomy.
- **Collaborative Adaptation:** Meaningful participation in leisure pursuits requires compromise, reinvention, and tailored strategies, enabling couples to sustain connection and relational satisfaction within neurodiverse partnerships.

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THANKS!

