



Well-being & Stress in Caregivers of Children with Autism

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Introduction

Background

- Caregivers who experience chronic stressors may experience physiological dysfunction such as depression, cardiovascular disorder, diabetes, certain cancers, autoimmune diseases, frailty and mortality.¹
- Self-determination theory suggests that key psychological needs for emotional well-being include **autonomy, competence and relatedness**.²

Purpose

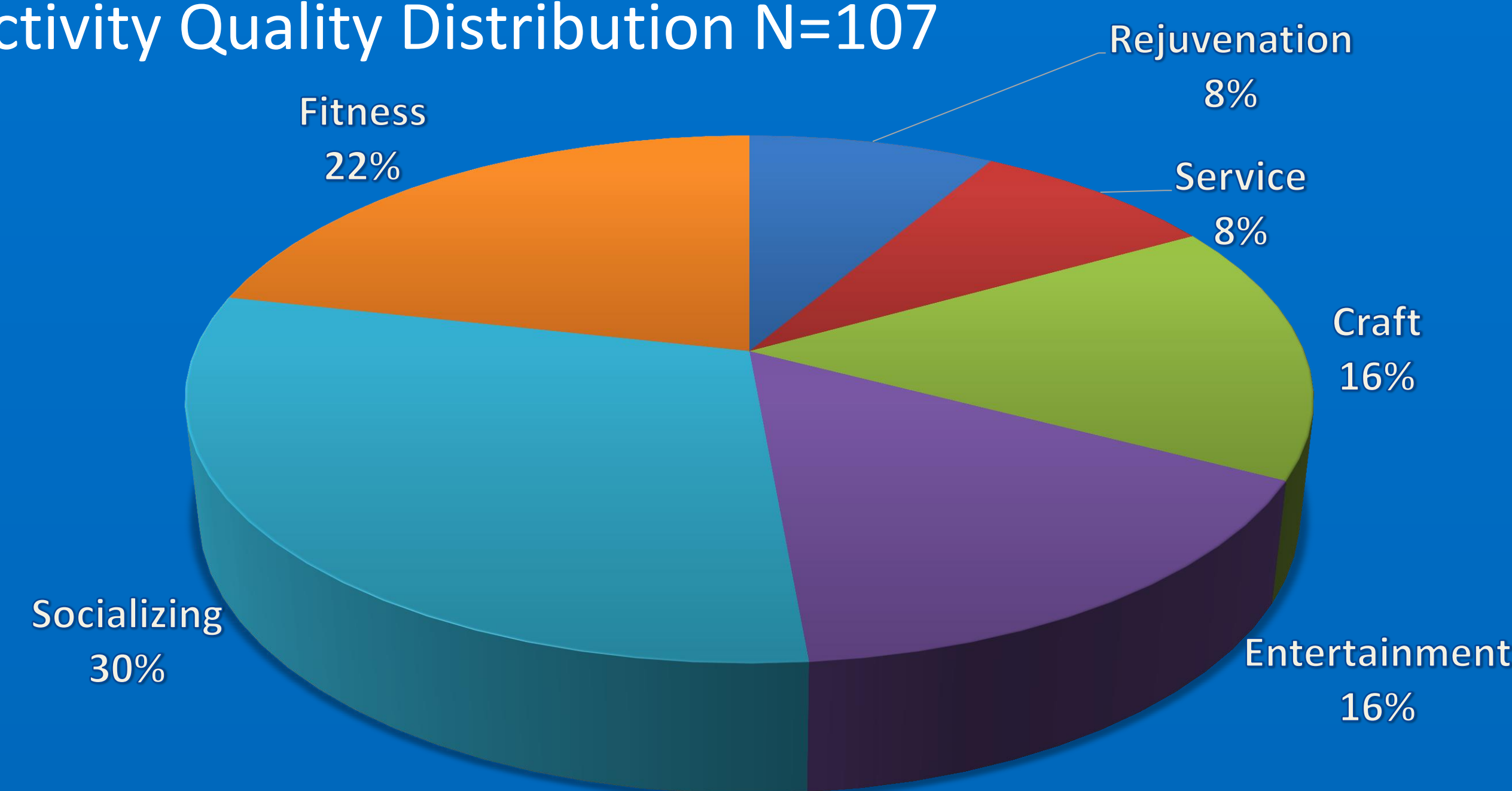
- Explore a client-centered occupation-based approach to foster well-being and diminish dysfunction for caregivers of children with autism.

Guiding Questions

- Which activities do caregivers of children diagnosed with autism desire to participate in more frequently?
- Which key needs of well-being do these activities meet?

Results

Activity Quality Distribution N=107



Caregivers listed 107 activities they desired to do more frequently. The majority of these desired activities were activities that allowed them to connect with friends, followed by more exercise. In the table below, it appears that socializing provided both a sense of competence and connection. Whereas exercise was typically experienced as promoting autonomy & competence.

Caregivers also desired more frequent opportunities to engage in entertainment & crafting. These seemed to provide a sense of competence & connection to others.

Overall, caregivers most often desired activities that enhanced their sense of competence or competence/connections. Only in exercise was the sense of autonomy dominant.

Conclusion & Implications for Practice

- Activities involving socializing were desired the most (30%)
- 86% of desired activities had qualities of competence.
- 45% of activities identified had qualities of both competence and relatedness.
- Activities representing autonomy only represented 23% of the total.
- Caregivers of children with autism surprisingly desired more opportunities to engage in activities which enhanced their sense of competence more than restful activities. This may counter their daily experience where they often engaged in continuous problem solving due to the fickle nature of their children's behavior.⁶ This finding aligns with recent research that noted work, for the same reasons of enhancing competence, was associated with higher well-being of caregivers.⁷
- OT interventions for this population should recognized that to foster wellness promotion new activities for caregivers need to generate experiences of competence & relatedness (rather than autonomy).

Design & Methods

This study is part of a larger participatory action research project by Dr. Elizabeth Larson at the University of Wisconsin-Madison called the Caregiver Lifestyle Redesign Project.

Participants

- 11 Primary caregivers of children with autism, ages 8-21 years, were recruited through autism conferences using opportunity sampling.³
- 90.9% Female
- Average age (SD) 49(±6.9)
- Average of child with autism 19(±5.4)
- 81.8% married
- 81.8% taking medication for a medical condition

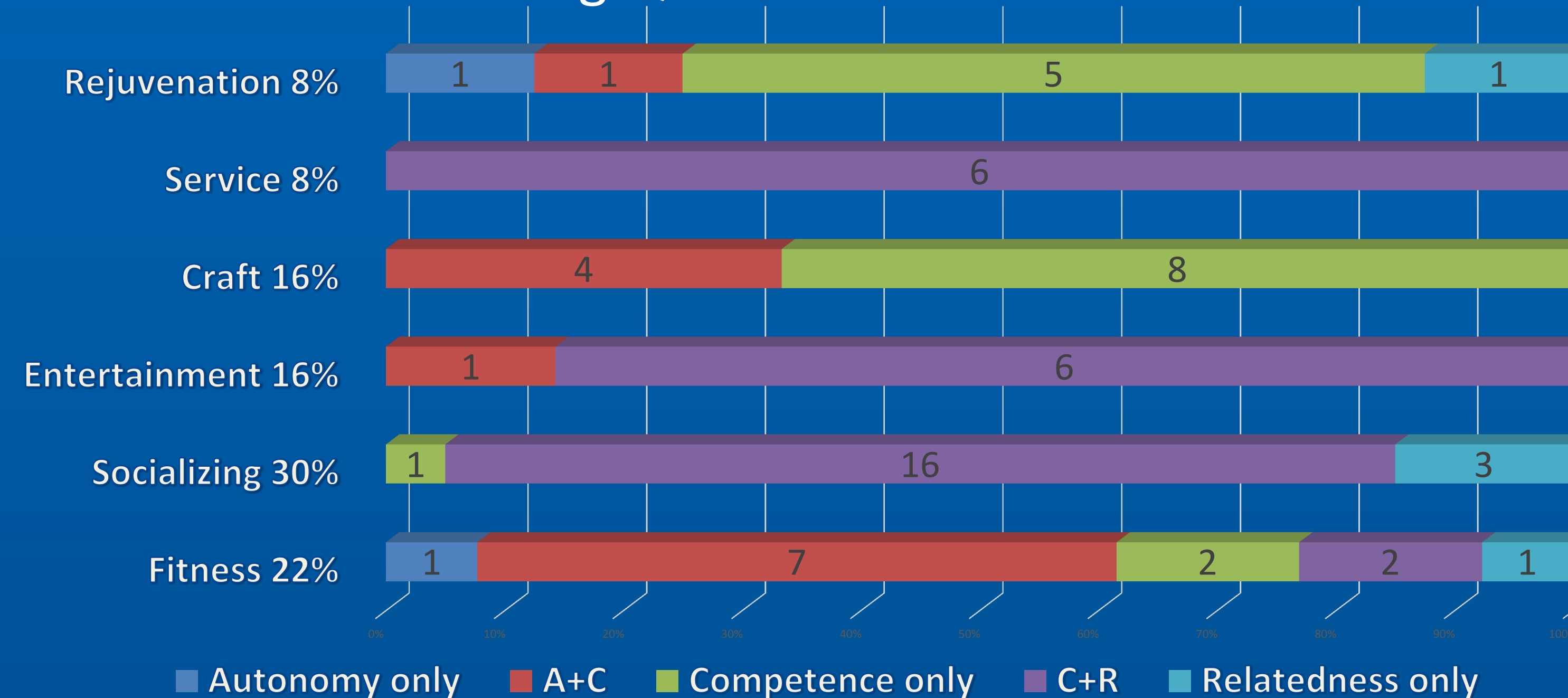
Data Collection

- Completed open-ended survey of activities caregivers identified as wanting to do more often.
- One-on-one interview using *Adolescent & Young Adult Activity Card Sort (AACS)* by Berg⁴ to elicit list of desired activities for goals.

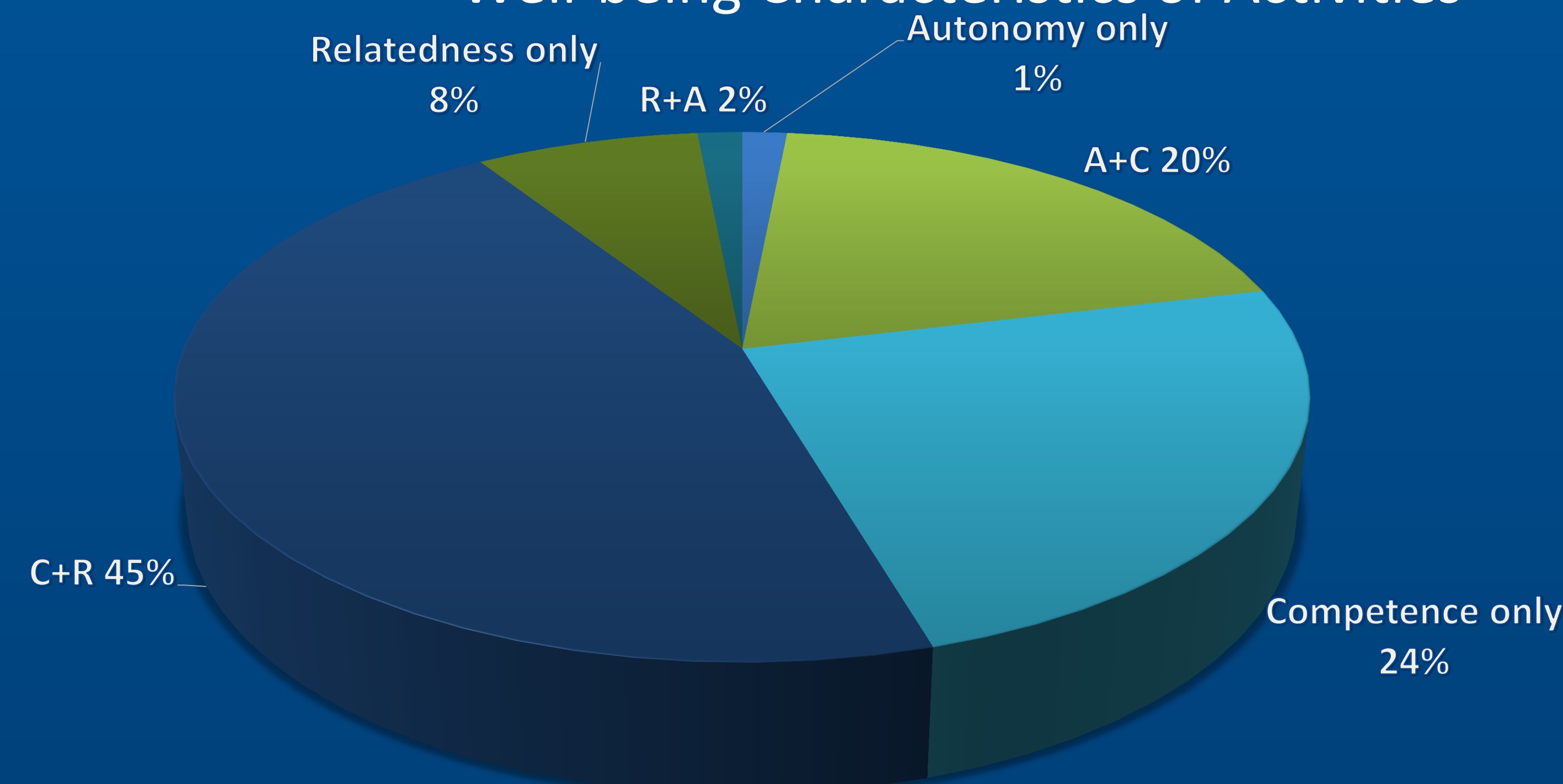
Analysis

- Activities categorized into: fitness, social, entertainment, craft, service, & rejuvenation. Activities done with another person were coded as social. Entertainment activities involved a form of media.
- Narrative data was analyzed using theoretically-derived well-being codes (autonomy, competence and/or relatedness)⁵ to identify whether the desired activity promoted these aspects of emotional well-being.

Well-being Qualities of Activities



Well-being Characteristics of Activities



References

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