

The Meaning of Work for People with Multiple Sclerosis: A Qualitative Study

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Background

- ✦ Employment is of great importance to adult life, with tangible benefits such as income and health insurance and intangible benefits related to psychological adaptation and purpose in life.
- ✦ Onset of multiple sclerosis (MS) typically occurs between ages 20-40, during the most active employment years, and presents significant challenges to maintaining or obtaining employment.
- ✦ As MS progresses, there is a sharp decline in employment, with only 20-30% employed 15 years after diagnosis and less than 50% in the US currently employed.
- ✦ Of those who left the workplace, the majority left their jobs voluntarily (75%), although most believe they are able to work and would like to re-enter the workforce.
- ✦ Rehabilitative support for employment varies substantially between individuals and states, and, typically, cases are closed by Vocational Rehabilitation (VR) after 90 days of employment.
- ✦ The philosophy of the current research is that employment after disability must be systematically investigated throughout the work life cycle rather than the focus on employment rate or case closures.

Purpose

The purpose of this study was to identify quality outcomes of employment, as defined by those with MS who have worked at some point following their diagnosis.

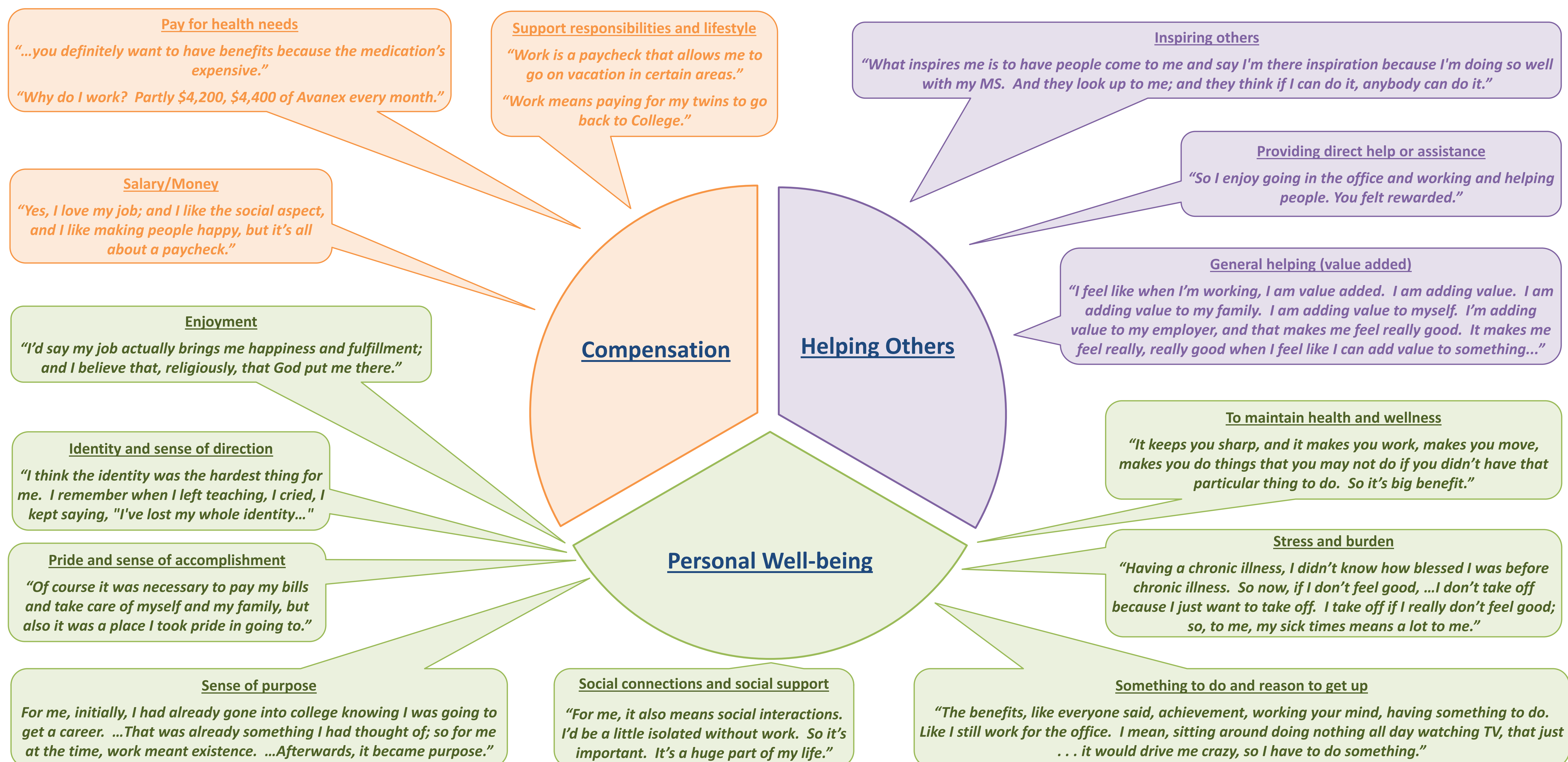
Methods & Participants

Qualitative approach using 3 focus groups at 3 sites (Ohio, Georgia, South Carolina) with a semi-structured interview format led by 2 group facilitators. Groups were heterogeneous., Inclusion criteria : (1) >18 years, (2) < 65 at time of diagnosis, (3) physical disability from MS, and (4) must have been employed after diagnosis.

Participants (N=74)

- ✦ Average current age: 46.79 years
- ✦ Average age at diagnosis: 34.63 years
- ✦ Average time post-diagnosis: 11.63 years
- ✦ 20.3% male
- ✦ 25.7% non-white

Identified Categories (3) & Themes (14)



Conclusions

We need to expand our focus from attempting to improve the portion of people that are employed after disability to a greater emphasis on the quality of employment *among those who have become employed* because the importance of work to the lives of people with MS and other disabling conditions can not be measured by employment rate alone. The emphasis on the employment rate obscures the importance of career development and associated benefits with participation, health, and quality-of-life.

Future research should work toward maximizing employment outcomes among those with disabling conditions, rather than focusing on return to employment or transition only and enhance prediction of changes in employment outcomes, which will allow for more accurate assessment of lifetime needs, such as is done in the life care plan.