

# Assessing the Vocational Impact of Chiari Malformation

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# Background and Overview

- Clinical manifestations of Chiari malformation (CM) are fairly well-documented (Fischbein et al., 2015; Mueller & Oro, 2004)
- However, little is known about the effects of CM on work outcomes and other aspects of people's work lives
- Two primary purposes of our research:
  - (1) provide descriptive data on the impact of CM on work-related experiences (e.g., job satisfaction and performance, coworker relationships)
  - (2) test the applicability of the Psychology of Working Theory (PWT; Duffy, Blustein, Diemer, & Autin, 2016) for individuals with CM

# Purpose 1: Descriptive Data

- We developed an online survey containing:
  - Established measures of key career development constructs (e.g., person-environment fit, job satisfaction)
  - Perceived work-related consequences of CM
- Data collected 2 ways:
  - 648 adults from the Chiari 1000 registry
  - Link to the survey on Conquer Chiari website
- Final usable sample included 323 working adults with CM

Table 1

*Frequencies and Percentages of Selected Work-Related Experiences Resulting from CM*

<b>Work-related experience resulting from CM</b>	<b>Number responding "yes"</b>	<b>% responding "yes"</b>
Negative financial impact*	227	72.8
Forced you to reprioritize career goals (e.g., seeking promotion)	219	70.4
Forced you to reconsider job values (e.g., good pay, satisfaction)	243	78.1
Influenced your decision to not pursue a potentially better career opportunity because changing jobs would be too risky	214	68.6
Influenced your decision to pass up other career opportunities because changing jobs might result in the loss of health insurance	165	53.2
Influenced your decision to remain in a job that was a poor fit with your abilities, values, and/or interests	147	47.4
Required a significant change in job duties	167	53.7
Required an overall job or career change	109	35.0
Required a cutback in hours at work	79	25.3
Forced a decision to go on disability	49	16.2

Table 1 (continued)

*Frequencies and Percentages of Selected Work-Related Experiences Resulting from CM*

<b>Work-related experience resulting from CM</b>	<b>Number responding “yes”</b>	<b>% responding “yes”</b>
Negatively affected job performance/productivity	67	22.0
Had a negative effect on your overall job satisfaction	187	61.3
Has had a negative effect on your relationships with coworkers	117	38.5
Will force you to retire earlier than you would like	186	61.4
Missed one or more days of work during the past year**	261	83.4
Worked one or more days during the past year in spite of experiencing CM-related complications***	280	94.9
Some level of anticipated discrimination from coworkers if they knew about your CM (e.g., some coworkers would like you less)	298	93.1
Experienced discrimination at work due to your CM (e.g., you were fired, you received a negative performance evaluation)	151	47.2

*Notes.*  $N = 295-323$

\*Median annual financial cost = \$5,000-\$10,000

\*\*Median number of missed work days = 6-10

\*\*\*Median number of days worked in spite of CM-related complications = 46-60

# Purpose 1: Descriptive Data

- Data indicate that CM has a number of significant adverse effects on the work lives of those with the condition.
- Two of those adverse effects—economic constraints and marginalization—figure prominently in the recently published *Psychology of Working Theory* (PWT; Duffy et al., 2016).
- Thus, the PWT is an ideal framework for studying the work experiences of those with CM.

# Purpose 2: Testing the Applicability of the PWT

- The central construct of the PWT (Duffy et al., 2016) is “**decent work,**” defined as work that affords:
  - safe working conditions
  - access to health care
  - adequate compensation
  - free time and rest
  - workplace values compatible with family and social values
- According to the PWT, **economic constraints** (i.e., limited resources) and **marginalization** (e.g., ableist workplace discrimination) are contextual barriers to securing decent work (see Figure 1).

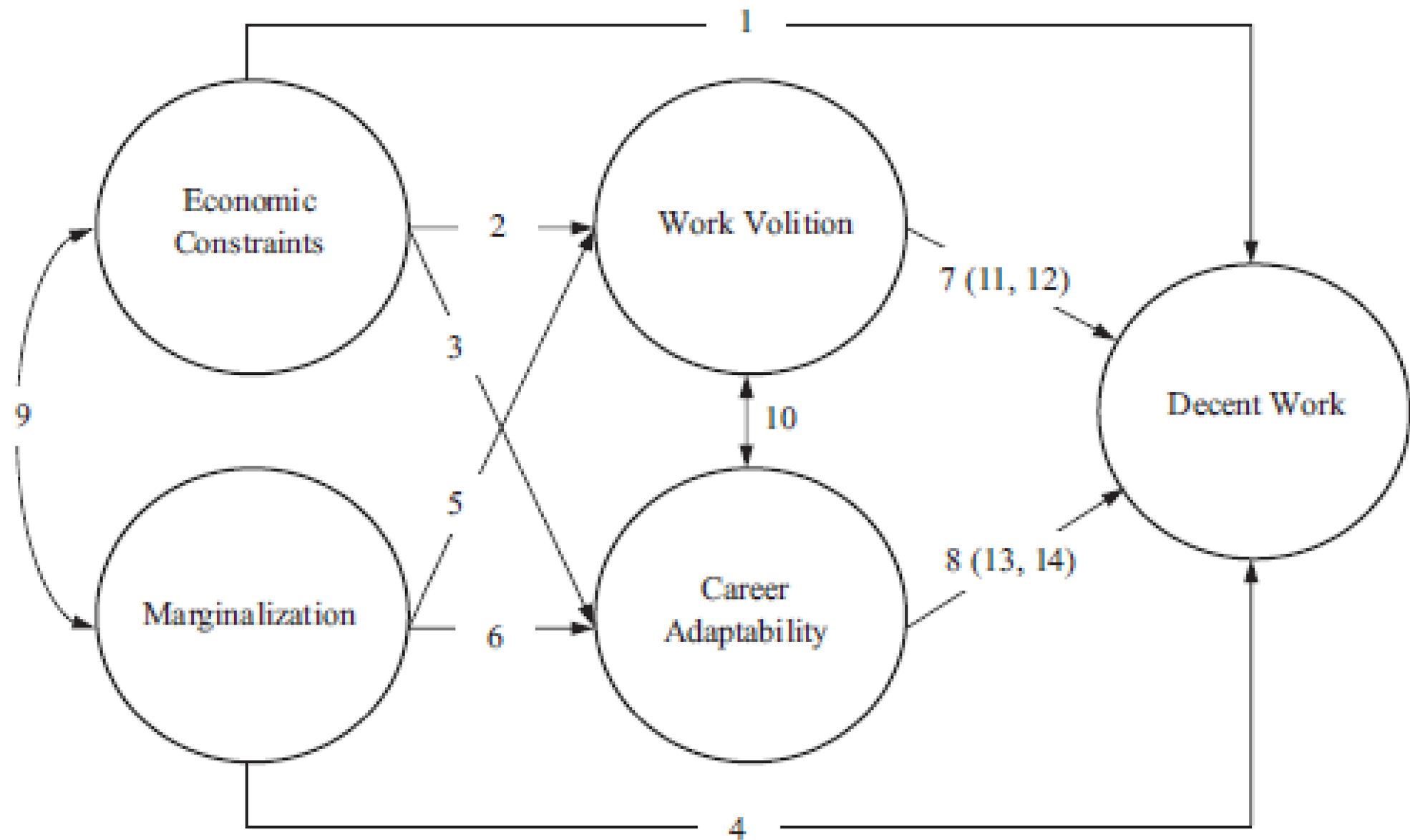


Fig. 1. Hypothesized structural model. Hypothesized indirect pathways are in parentheses. Conceptual adaptation with modification from Douglass et al. (2017).

# Purpose 2: Testing the Applicability of the PWT

- Economic constraints and marginalization are posited to limit people's ability to secure decent work both directly and indirectly.
- Indirect effects are via their effects on:
  - **work volition** (perceived career decision-making ability despite constraints)
  - **career adaptability** (coping resources for career-related challenges).

# Purpose 2: Testing the Applicability of the PWT

- Data collection included measures of PWT constructs.
  - e.g., a measure of perceived discrimination faced by individuals with any chronic health condition (in this case, CM)
- Results of structural equation modeling analyses indicated that the hypothesized model fit the data well; thus the PWT appears to be a useful framework for predicting decent work among individuals with CM.
- Figure 2 (next slide) summarizes the standardized parameter estimates for hypothesized PWT paths.

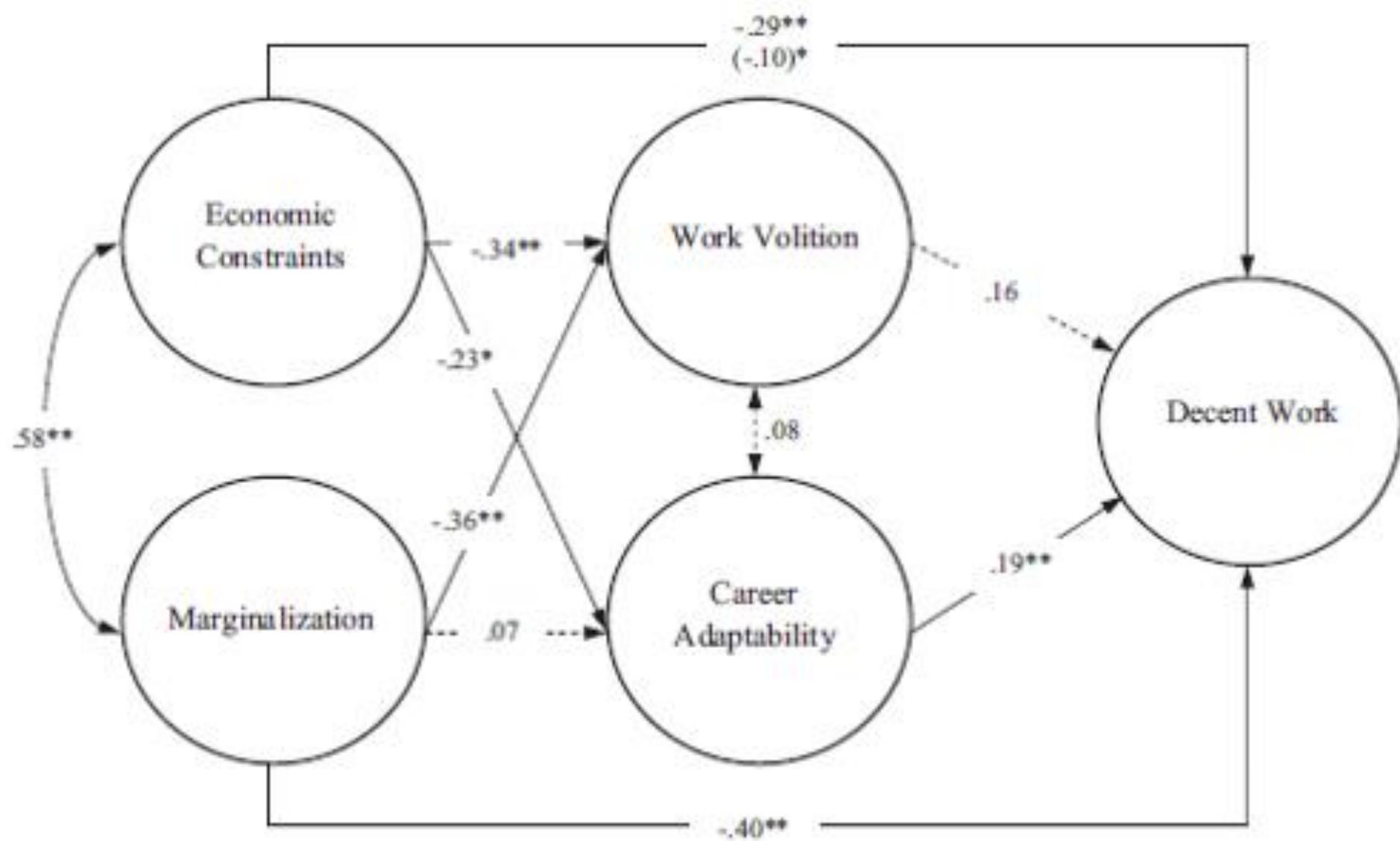


Fig. 2. Standardized parameter estimates for the hypothesized structural model. The unstandardized indirect effect from economic constraints to decent work via career adaptability is presented in parentheses.  $*p < .05$ ,  $**p < .01$ .

# Purpose 2: Testing the Applicability of the PWT

- Notable findings:
  - having fewer economic resources and experiencing more ableist discrimination were perceived as substantial barriers to securing decent work
  - having fewer economic resources and experiencing more ableist discrimination also were associated with a diminished sense of control in career decision making (i.e., less work volition)
  - having fewer economic resources was associated with a reduced capacity to adjust to career-related challenges (i.e., less career adaptability)

# Future Directions

- We plan to explore some of the PWT's posited outcomes of decent work—including work fulfillment (e.g., job satisfaction) and overall well-being—among workers with CM.