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## **Disclosure or Concealment: How Employees Caring for Dependent Older Adults and Those with Disabilities Manage the Communication Boundaries at Work**

Lisa M. Stewart

Avelina Charles

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8<sup>th</sup> Community, Work and Family Conference

## Disclosure or concealment:

# How employees caring for dependent older adults and those with disabilities manage the communication boundaries at work

Lisa M. Stewart, Ph.D.  
Avelina Charles, B.S.W.

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# Work-life Issues of Employees with Exceptional Care Responsibilities

- *Exceptional care* is characterized by intense, cyclical and crisis-driven demands (Roundtree & Lynch, 2007).
- Care demands produce unique **intersectional burdens** for employees who experience higher levels of work-family conflict compared to workers caring for young children of typical development, and to some degree, those caring for older adults (Stewart, 2013).
- Absence of specialized resources in community lead employees to look towards the workplace for flexibility (Timmermans & Freidlin, 2007)
- Employees with exceptional care responsibilities face courtesy **stigmatization** and **discrimination** at work (Eales et al., 2015; Rosenzweig et al., 2011).
- Communication competence has been identified as a facilitator in the successful negotiation of workplace supports (Stewart, Rosenzweig, Brennan, & Malsch, 2019).

# Theoretical frameworks and Research Focus

- Drawing on the **Continuum of dependent care model** (Stewart, Stutz, & Lile, 2018) distinguishes care activities as occurring along a continuum we explored disclosure and communication competence for two groups of employed caregivers.
- **Lifecourse fit** (Moen, 2011) was used to frame disclosure decisions employees caring for children and younger adults with disabilities and those caring for older adults make when approaching employers for flexibility.
- **Border/Boundary theory** (Ashford, Kreiner, & Fugate, 2000; Clark, 2002) used to explore the boundary dynamics such as negotiation, and transition across work and family lines.
- **Research focus:** Extend model of **Boundary Communication Management** (Rosenzweig et al., 2011) to include disclosure and communication decisions made by employees caring for children and younger adults with disabilities and those caring for older adults.

# Methods – Procedure

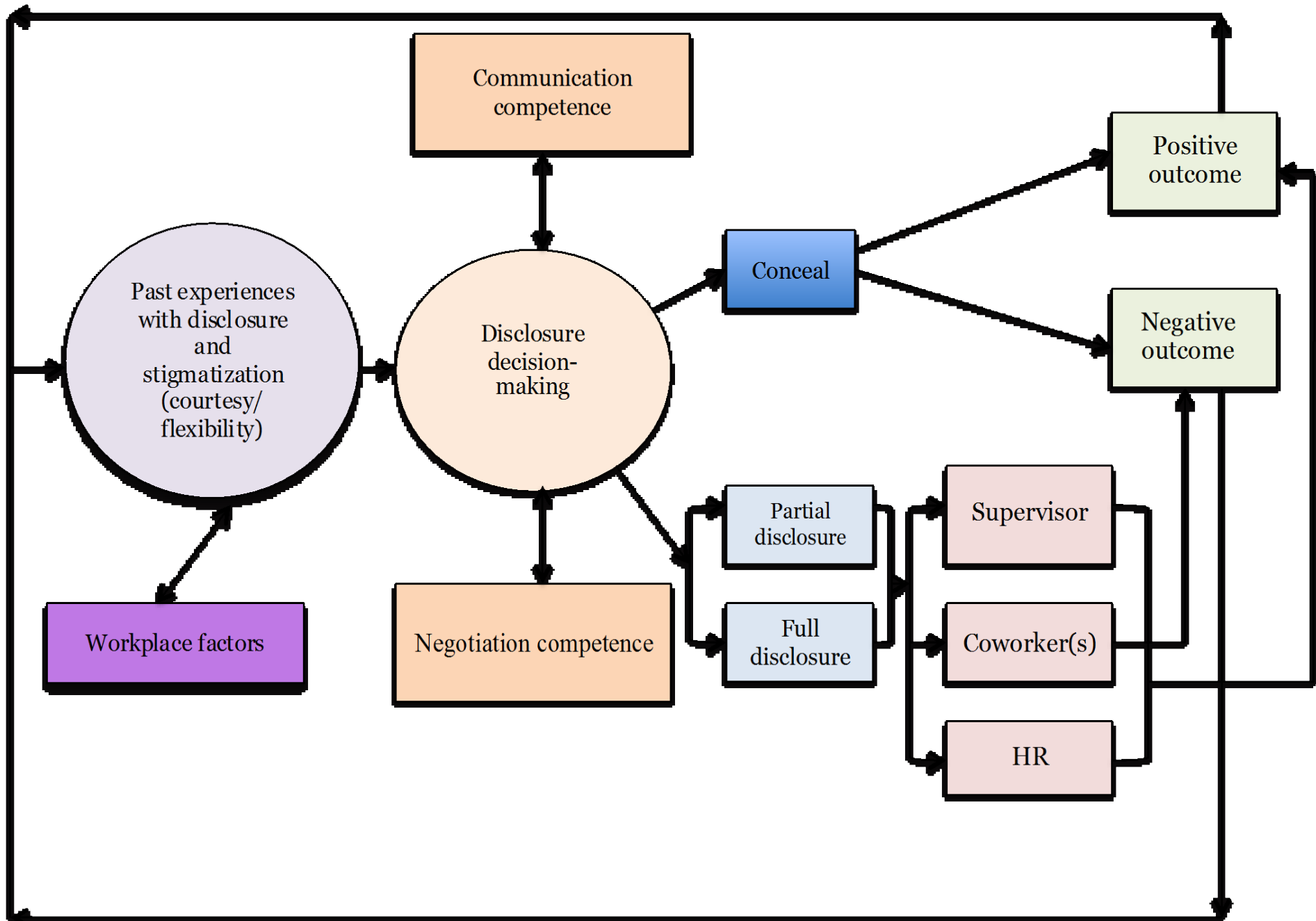
- Sample recruited through a larger employee survey of university employees (staff, faculty and managers).
- Participants screened to ensure variability in sample (caregiving type, job type, gender).
- Semi-structured interviews were selected over focus groups given the sensitive nature of the data and the fact participants came from a single small organization.
- Questions based on Rosenzweig et al. focus group guide and literature review.
- Prior to start of interviews, informed consent collected and demographic questionnaire administered; permission to digitally record and transcribe interview obtained.
- Axial coding using a constant comparative method used to develop grounded theory model.

# Methods – Sample Demographics

- **19 employees caring for children, younger adults with disabilities or those who cared for older adults**
  - 11 participants provided care for a child or younger adult with a disability.
  - 8 participants provided care for an older adult.
- **Age** ( $M = 47.40$  age in years;  $SD=2.77$ ).
- Participants identified as non-Hispanic White (57.8%), Hispanic/Latino (15.7%), or more than one race at (26.3%)
- **Female** (89.4%).
- **Graduate degree** (68.4%).
- **Time in job** ( $M=7.24$ ;  $SD= 3.12$ ).
- **Hours spent in direct care:** Total ( $M = 54.68$ ,  $SD = 18.02$ ); Children/Young adults ( $M = 72.7$ ,  $SD =49.47$ ); Older adults ( $M = 36.66$ ,  $SD =4.6$ ).



**Figure 1. Model of Boundary Communication Management Decisions and Strategies Used by Employees with Exceptional Care Responsibilities**



# Past Experiences with Disclosure and Stigmatization

From Rosenzweig et al., 2011

## Disclosure

- **Conceal**: Maintain perception of “normal” family life.
- **Partial disclosure**: Tell some but not all information related to the disability and the care role.
- **Full disclosure**: Tell everything related to the disability and the care role.

## Stigmatization

- **Direct stigmatization**: being the recipient of stigmatizing attitudes and behaviors.
- **Indirect stigmatization**: observing stigmatization directed towards others.
- **Perceived stigmatization**: person construes or anticipates stigmatization without observable evidence (Rusinova, Nicolellis, & Rapp, 2006).
- **Internalized stigmatization**: directing stigmatizing attitudes towards oneself.





# Communication and Negotiation Competence

- Knowing when to tell (never, during interview in anticipation of crisis, as time in position lengthens, during crisis).
- Knowing how much to tell (conceal, partially disclose, fully disclose).
- Knowing who to tell (supervisors, co-workers, HR).
- Understand before disclosing what is available/possible (informal, formal supports).
- Understanding workplace context (culture, job role).
- Having relational capacity with supervisors and coworkers.
- Negotiate with promise (Rosenzweig et al., 2011).



# Outcomes of Disclosure Decisions

	Positive	Negative
Disclosure (Partial/Full)	<ul style="list-style-type: none"> <li>Obtain social support (emotional, instrumental)</li> <li>Access flexible work arrangements</li> <li>Access to formal supports (FMLA, CPFL)</li> </ul>	<ul style="list-style-type: none"> <li>Stigmatization (<i>courtesy, flexibility</i>)</li> <li>Equity concerns</li> <li>Scrutiny</li> <li>Co-worker resentment</li> <li>Job loss/Loss of insurance</li> </ul>
Concealment	<ul style="list-style-type: none"> <li>Avoid stigmatization (<i>courtesy, flexibility</i>)</li> <li>Avoid equity concerns</li> <li>Avoid scrutiny</li> <li>Avoid resentment</li> <li>Maintain employment</li> <li>Escape home life</li> <li>Maintain “normal” work life</li> </ul>	<ul style="list-style-type: none"> <li>No access to social supports (emotional, instrumental)</li> <li>No flexible work arrangements</li> <li>No access to formal supports (FMLA, CPFL)</li> </ul>



# Discussion and Implications

- Employees engaged in exceptional care make **careful decisions** about **when, who** and **what to tell** regarding their dependent(s) health care status.
- Decisions based on **past experiences** with **disclosure** and **stigmatization**.
- Supports **Continuum of Dependent Care model** (Stewart et al., 2018) suggesting intensity, typology and complexity influence demands of support within workplace ecologies.
- Findings extends understanding of **Boundary of Communication Management model** demonstrating similar **communication strategies** across exceptional care groups and directed towards supervisors and coworkers (Rosenzweig et al., 2011).
- Findings confirm notion that communication competence is **learned, contextual and relationally** embedded (Steele & Plenty).
- Future research needs to explore ways develop effective interventions targeting communication competence training which supports employees with exceptional care responsibilities negotiate for the flexibility resources needed to achieve lifecourse fit (Moen, 2011).

