FUTURE OF WORK IN HEALTH CARE TEAMS: BRIDGING THE GAP BETWEEN “FORMAL” AND “INFORMAL” CAREGIVERS

Mina Raj, PhD
Kinesiology and Community Health
Aging, Caregiving and Technology Lab
University of Illinois Urbana Champaign
Acknowledgements

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Family caregivers of adults are increasingly important within the health care system.

- Coordinating care between providers
- Advocating for patient's needs
- Navigating social and cultural differences
- Providing information about patients' health to providers
- Communicating with providers in person and via health record

*Amplified role during pandemic

Wolff, Freedman et al (2020), JAMA
Iott, Raj et al (2020), Journal of General Internal Medicine
Yet they are not recognized within the health care team
...despite demonstrating trust-based relationships

“As far as objective information, data are concerned, I would definitely lean towards the physician. But when it comes to assessing the whole environment, it is, I think, definitely a family member who is in a better position and generally, able to provide more detail that the physician may not even be aware of.” -P11

“If talk to the caregiver, I get a different perspective. For example, nausea, symptom burden, or fatigue, the referring physician will tell me, ‘He doesn’t have a lot of fatigue, he’s doing fine.’ But then when you talk to the caregiver, they tell us that ‘He’s doing very bad, he’s not able to walk.’” -P10
And despite increasing policy imperative to integrate...
Why?

- Hierarchical history of medicine
  - Formal ("professional," "paid," "trained") vs informal
  - Discourage information sharing → Information asymmetry
- Permanence of team members vs dynamic entry of caregivers
- Under-recognized value
- Ambiguous definition of caregiver’s role in the team

Klocke 2007
Busche & Chu, 2011
Doekhie et al, 2017
Scoping review: How has care partner inclusion been measured and defined?

- N=45
- Outpatient settings
- Observational (n=38), interventional (n=9)
- How do identified articles describe care partners?
- How do identified articles define and describe care partner involvement in health care teams?
Key Elements of Reviewed Research

• Considers caregivers through lens of decision making, disease management, daily living assistance, and communication with physicians/medical staff.

• Shows mixed perception of inclusion by caregiver; perceptions of care coordination viewed through various measurement instruments.

• Notes caregiver responsibilities as burdensome, impacting wellness; highlights interventions meant to support/improve skills of caregivers.

• Examines electronic devices in terms of how they support or improve care as well as their ease of use on patient and caregiver outcomes.
Key Elements of Reviewed Research

Defining and Operationalizing Caregiver Inclusion
- Considers caregivers through lens of decision making, disease management, daily living assistance, and communication with physicians/medical staff.

Care Coordination
- Shows mixed perception of inclusion by caregiver; perceptions of care coordination viewed through various measurement instruments.

Caregiver Wellness and Interventions
- Notes caregiver responsibilities as burdensome, impacting wellness; highlights interventions meant to support/improve skills of caregivers.

Technology and Access
- Examines electronic devices in terms of how they support or improve care as well as their ease of use on patient and caregiver outcomes.

Opportunities for Future Research

- Should address team-building support and clearly identify how caregiving tasks fit into healthcare teams; identify how formal hierarchy as well as trust may impede or facilitate inclusion.

- Could determine optimal flows of communication; evaluate patient outcomes associated with caregiver involvement; determine role of shared team goals and trust; assess leadership’s role in coordination.

- Could identify efficacy of interventions aimed at knowledge and skill development or caregiver burnout reduction.

- Discover interdependencies between caregiver and medical staff that could be facilitated by technology; identify the privacy implications of using technology as a tool for caregiver inclusion.
Implications for the future of work

- Health care organizations will face increasing pressure to involve family caregivers
  - Post pandemic, societal aging, resolving information asymmetries, policy (e.g., RAISE Act)

- Policy needs to stay a step ahead to support organizations and caregivers
  - E.g., technology policies, payment policies
Implications for the future of work

- Evolving norms and definitions of “professionals” and “formal workers” and their roles in health care
- Changing norms of teamwork and channels for communication within teams
- Who gets paid, how, and for what?
  - Compensation for caregivers to recognize their involvement?
  - Compensation for physicians for formally including caregivers?
- Thinking broadly and creatively about who else might be involved in health care work
  - Behind-the-scene workers
THANK YOU

mraj@illinois.edu