Enhancing the Person and Family Centered Nature of Long COVID Care for Adults: A Qualitative Study

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Background & Objective

- **Long COVID (LC)** affects 10-39% of COVID-19 survivors.[1]
- **Adults with LC (AwLC)** face diagnostic delays, inadequate treatment, and medical gaslighting.
- **Caregivers** experience high stress and burnout from demanding care responsibilities.
- **Healthcare providers (HCPs)** have limited LC knowledge, causing delays & reduced patient trust.
- **Person- and Family-Centered Care (PFCC)** prioritizes collaboration to improve care by addressing needs, preferences, and contexts.
- **Study Objective:** explore the experiences of AwLC, caregivers, & HCPs regarding PFCC in the LC context.

Methods

- **Design:** Qualitative descriptive study using virtual, semi-structured interviews.
- **Sample:** AwLC (n = 3), caregivers (n = 3), and HCPs (n = 3) recruited via online support groups, LC networks, and snowball sampling.
- **Data Collection:** Interviews cover care planning, collaboration, family influences, policies and procedure, education, and care coordination.
- **Data Analysis:** Thematic analysis, with rigor ensured through reflexive journaling, audit trail, and rich descriptions.

Results

The following **preliminary themes** emerged from interviews with **three AwLC:**

1. **There are personal and social consequences of long COVID** (e.g., loss of employment, chronic fatigue, social isolation, cognitive impairment, difficulty accessing healthcare).
2. **Accessing care for people with long COVID could be improved.**
   a. Patients must self-advocate to access adequate and needed care.
   b. Limited healthcare resources and providers leave this population underserved.
   c. A care coordinator and central information hub is needed to navigate the fragmented healthcare system.
3. **Family members provide essential support to people with long COVID and require support.**
   a. A strong caregiving and social network is essential for health and well-being.
   b. Families need education on their shifted roles and care expectations for AwLC.
   c. HCPs fail to consider social support and context in care plans.
4. **The public health system needs to support this population.**
   a. Public, social circles, and HCPs have limited awareness of long COVID's impact.
   b. Limited public health support leaves people with long COVID feeling erased.
   c. Better infection prevention and control measures are needed for accessible, safe care

Conclusion/Implications

- **Increase education and awareness** of LC among healthcare providers, public health, and the general public to improve care delivery and misconceptions.
- **Integrate PFCC approaches** to incorporate social support and family context into care planning.
- Establish care **coordinator roles and centralized information hubs** to streamline care and provide timely resources for patients, caregivers, and HCPs.

Next Steps

Finish interviews with caregivers and HCPs, analyze the data, present findings at OS&OT Graduate Research Day, and prepare the manuscript.

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References

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