

# Comprehensive Assessment of Lived Experience and Burnout In Caregivers of Transitioning Young Adults with Childhood Medical Complexity in Alabama: A Mixed Methods Approach

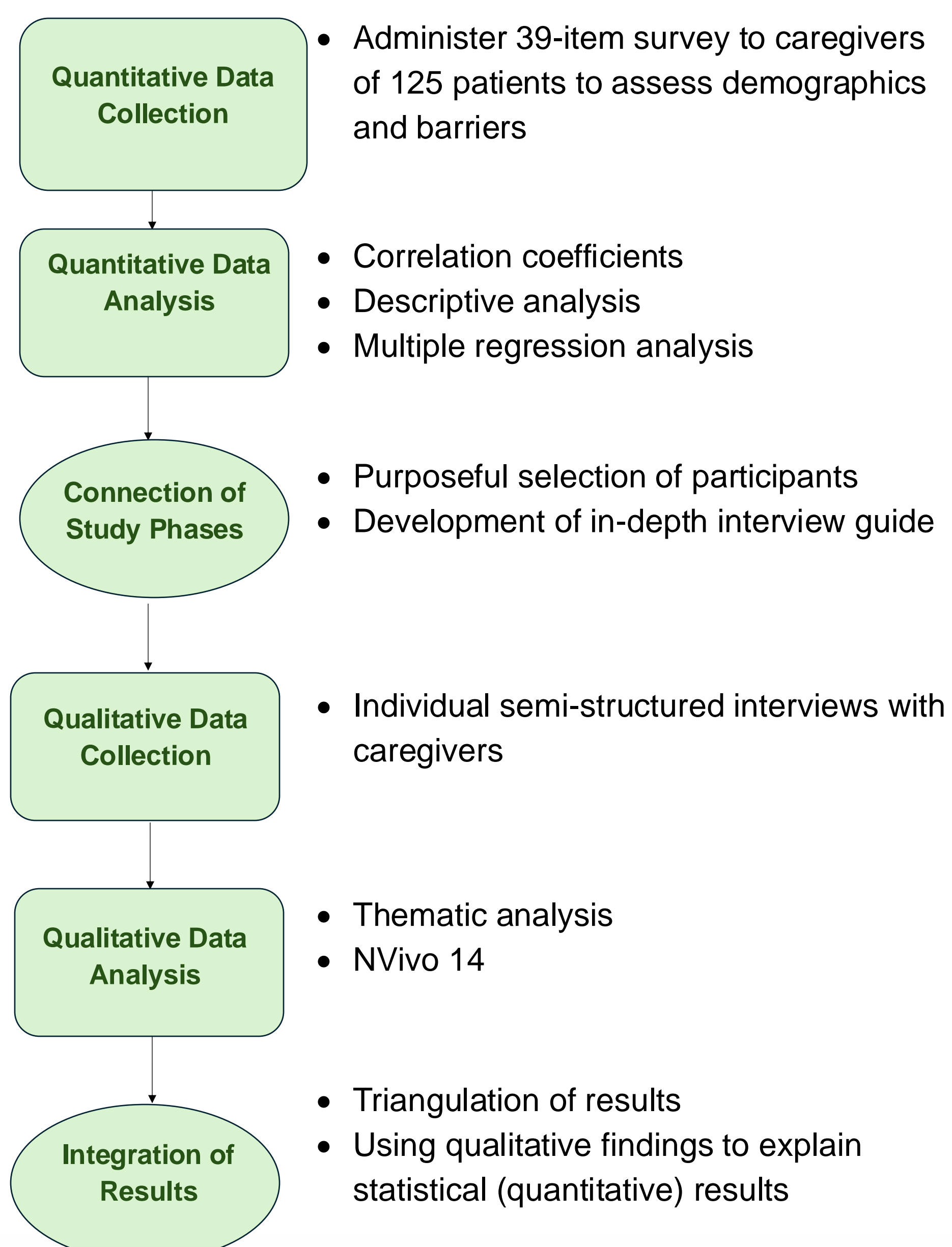
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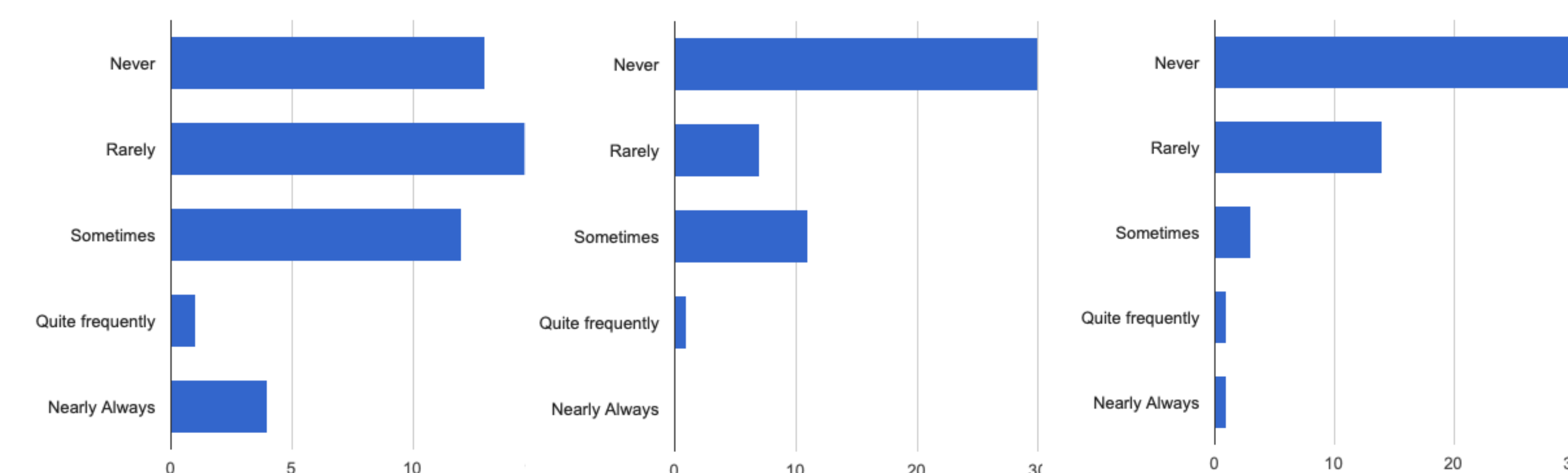
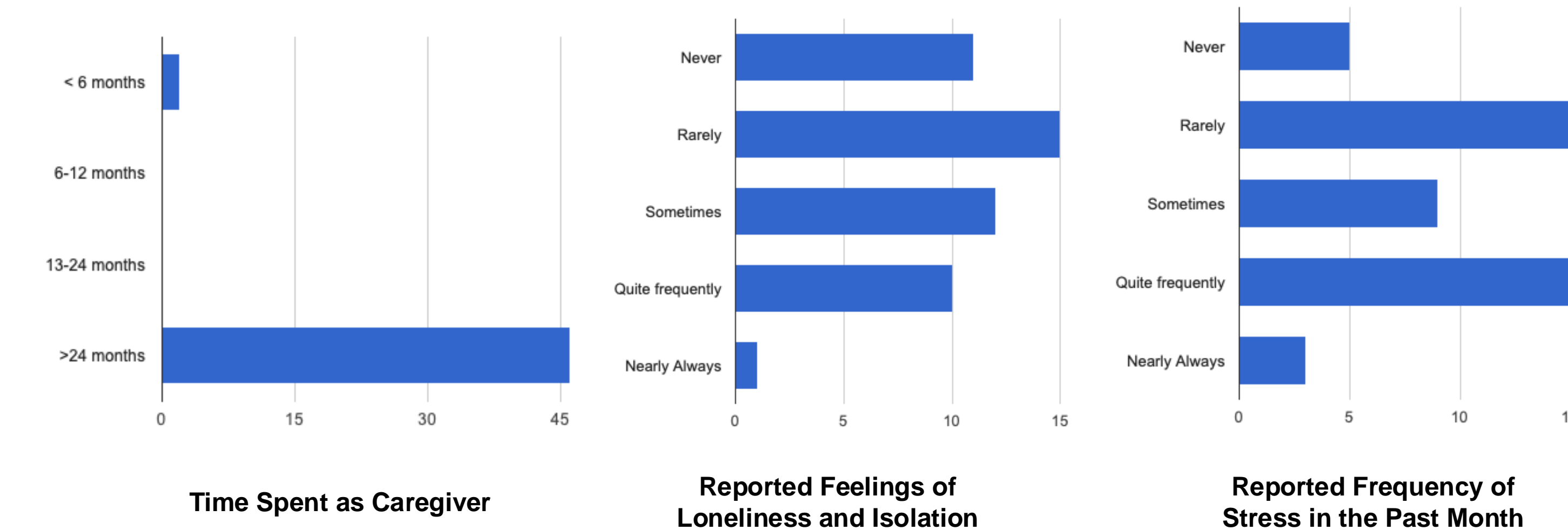
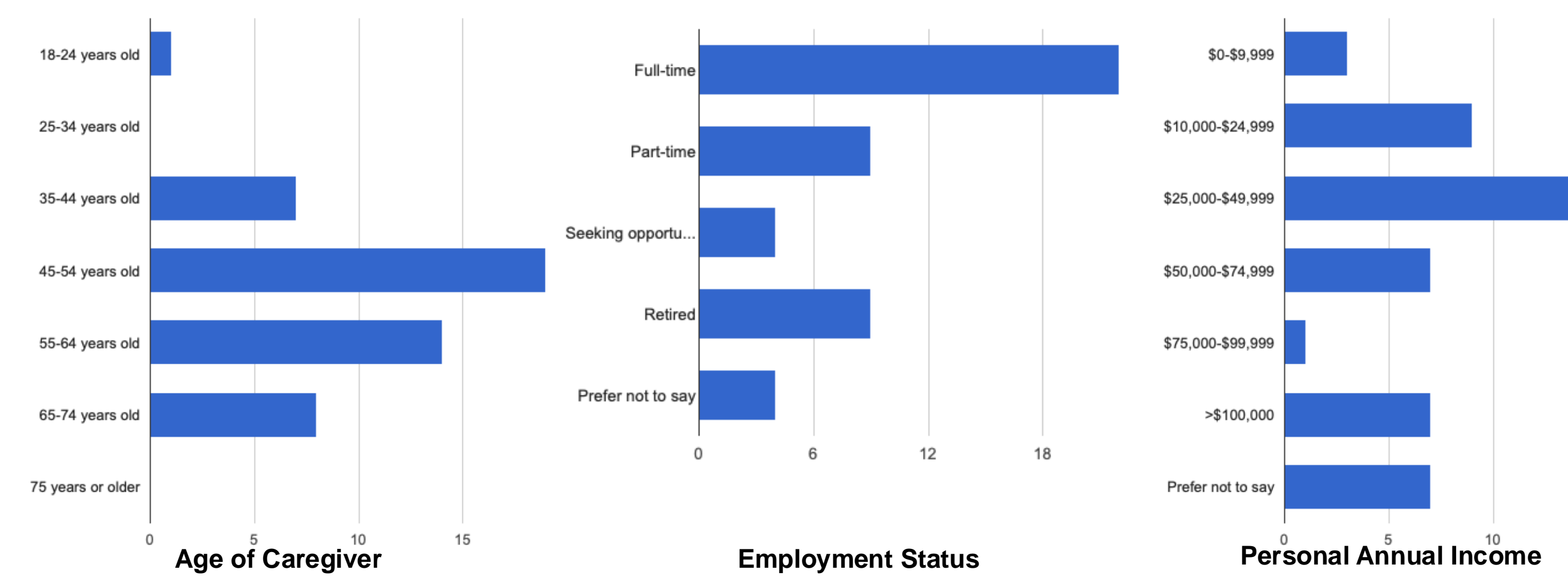
## Background

- Adolescents with complex medical conditions often require ongoing care
- There is a greater need for primary care clinics to support patients with chronic conditions
- Patients with complex medical conditions are susceptible to poor health outcomes
- “Staging Transition for Every Patient” (STEP) program at University of Alabama at Birmingham (UAB) is designed to prepare young adults with complex conditions
- Understanding caregivers’ experiences and challenges allows for clinicians to not only meet the caregivers’ needs and minimize burnout, but also optimize patient care and safety

## Methods



## Results



“In the last month, how often have you: Found that you could not cope with all the things you had to do?”

“In the past 12 months, has lack of reliable transportation kept you away from appointments?”

“In the past 12 months, have you faced the possibility that your phone, internet, electricity, gas, or water services could be stopped at your place of residence?”

## Results, cont.

- Forty-five percent of caregivers are above 55 years of age
- Forty-six percent of caregivers reported their status as full-time employees
- The income of 55% of caregivers was at or below \$49,000 in the past year
- Ninety-six percent of surveyed participants have served as a caregiver for over 24 months, or 2 years
- Seventy-eight percent of caregivers report feeling varying degrees of loneliness and isolation.
- Over 89% of caregivers report feeling varying degrees of stress in the past month
- Over 72% of caregivers report feeling as though they were unable to cope with their responsibilities in varying degrees
- Thirty-eight percent of caregivers report a lack of reliable transportation
- Thirty-eight percent of caregivers report facing the possibility that their services could be stopped at their place of residence in the past year

## Conclusions

- Results are proving the significance of burden through the transition for the caregivers
- Isolation and lack of resources are early findings that need further exploration
- Qualitative data will allow greater opportunity to develop interventions to reduce burden in vulnerable populations

## Implications

- This study may inform providers of the specific challenges faced by caregivers in Alabama to improve resources and offer more streamlined support
- Caregiver well-being is closely linked to patient outcomes
- Insights from the study may lead to development of holistic care models that not only consider the patient’s needs, but also the caregiver’s well-being
- The study may introduce a need to develop educational programs or support groups for caregivers

## Institutional Review Board (IRB)

This study has been approved by the Institutional Review Board of the University of Alabama at Birmingham, under the title “The development of a transition program for patients with medical complexity, STEP Program, and given the code IRB-300007699.