

# The costs and consequences of providing unpaid care to people living with dementia in middle-income countries

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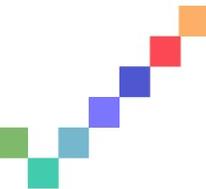
# DEMENTIA AND EQUITABLE SOCIETY

- Most people with dementia live in low and middle-income countries
- Inadequate formal and informal care services, fragmentation of care pathways that do exist and low rates of diagnosis means that care for people living with dementia is **primarily provided by unpaid family members**
- Reliance on informal care is likely to **reflect and contribute to inequities within and between countries**. Globally, informal caregivers are more likely to be women, be from lower socioeconomic groups. **Negative consequences of caregiving are unequally distributed**
- However, **research into the complex realities of providing unpaid dementia care** outside high-income countries is in its **relative infancy**



# MANY UNANSWERED QUESTIONS

- What economic or social value should be given to carers' unpaid labour if they are unlikely to have regular salaried employment if they weren't providing care?
- Or if they, their family and/or their community had low expectations of the economic contribution they would make had it not been for caregiving?
- Or if we don't know what the cost of buying alternative care would be?
- How does the financial cost of providing dementia care differ between those with some limited resources and those with none?



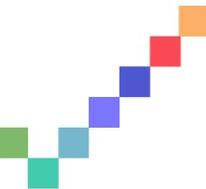
# MANY UNANSWERED QUESTIONS

- What is the direction of flow for financial resources between those providing and those receiving dementia care?
- How can we understand what the social costs of providing dementia are when we don't know if, how, or why care is shared among multiple members of households?
- In India, existing research suggests that gender shapes the economic, social and health consequences of providing care for people with psychosocial disabilities differently for men and women, with the asymmetry of a greater burden for women (Mathias et al. 2018). What about other existing fault lines?



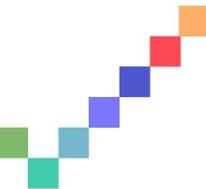
# OUR AIM

- These questions need answering before the costs and consequences of unpaid care to individuals and societies can be **measured** and **interpreted meaningfully**
- Study aims to **explores these complexities** by considering three **distinct case studies** of caregiving experiences in **India, Jamaica, and Mexico**
- It forms part of the wider **Strengthening responses to dementia in developing countries (STRiDE) Project**, a multidisciplinary collaboration across seven countries to support the development and evaluation of National Dementia Plans

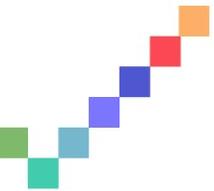


# HOW

- Carrying out **inductive, iterative** qualitative work with **people who care or have cared, without pay, for someone with dementia** in each setting
- **Multiple interviews** with each participant
  - Increases range of topics and depth of discussion
  - Appropriate for data that privilege process
  - Encourages inconsistencies and unexpected relationships
  - Meets challenge of non-linearity and omissions in people's narratives
  - Gives participants opportunity to verify both our understandings and early analytical interpretations



# COVID-19



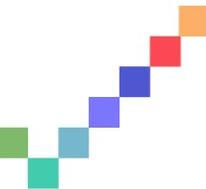
# HIGHLIGHTING INEQUITIES

- COVID-19 pandemic likely to highlight and possibly exacerbate inequities in whether and how providing unpaid care to a family member with dementia presents a burden to caregivers
  - Pandemic presents a **period of potential crisis** for people caring for those with dementia:
    - Caregivers and people with dementia **at-risk from virus**
    - Caregivers **at-risk from physical and social distancing and the suspension or reduction of service**
  - Should either the pandemic, or responses to the pandemic, significantly affect participants' daily lives, this period is likely to throw into relief participants' **resilience to crisis and their coping mechanisms**, or conversely, **the fragility of the care systems they have constructed and their experiences of them**
- Data about COVID-19 experiences are likely to help us better understand the broader costs and consequences of providing unpaid care, as well as the impact of the pandemic on care systems



# A NEW EVIDENCE NEED

- Important to capture these experiences of the pandemic as it unfolds
- Data needed to highlight:
  - impact of response measures on caregivers during the pandemic
  - legacy of additional care and support needs that these responses may generate and that will need to be addressed when in-person services resume
- Evidence may also be utilised to support the development of government responses to future national or international emergencies that are appropriate for these populations

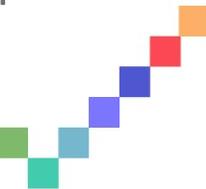


# GENERATING DATA

Several revisions to research methodologies have been necessary

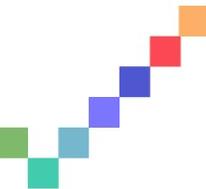
Among them, generating data on caregivers' experiences of COVID-19 pandemic in all three countries:

- ➔ **Jamaica** Series of short 'check in' calls with existing participants to generate observational data to be analysed alongside interview data generated pre-March 2020 and shape any further generation of remote interview data
- ➔ **Mexico** Series of short 'check in' calls with existing participants complemented by extended discussion of COVID-19 as part of remote in depth interviews with all participants commencing October 2020
- ➔ **India** Discussion of COVID-19 experiences as part of full programme of remote in depth interviews with all participants commencing November/December 2020



# WHAT'S NEXT?

- Results expected end of 2021
- Delays experienced with our research also presents an opportunity: the research – and the evidence we produce – can still be influenced and shaped
- Please get in touch!



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