

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

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OS31: Dementia as a public health priority - Dementia and equitable society

Alzheimer's Disease International Virtual International Conference
10-12 December 2020

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**. We know that globally, informal caregivers are more likely to be women, be from lower socioeconomic groups and that **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 in MICs differ between those with *some* resources (middle wealth) and those with none (lowest wealth groups)?



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 of inequity?



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 **explore 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!



ACKNOWLEDGMENTS

- Suvarna Alladi (STRiDE India)
- Rochelle Amour (STRiDE Jamaica)
- Adelina Comas-Herrera (STRiDE Co-PI)
- Sarah Drew (STRiDE unpaid care)
- Nicolas Elias (STRiDE Jamaica)
- Rosa Ma. Farrés (STRiDE Mexico)
- Ishtar Govia (STRiDE Jamaica)
- Saadiya Hurzuk (STRiDE India)
- Martin Knapp (STRiDE PI)
- Mariana López-Ortega (STRiDE Mexico)
- Anji Mehta (STRiDE project management)
- Meera Pattabiraman (STRiDE India)
- Jayeeta Rajagopalan (STRiDE India)
- Narendhar Ramasamy (STRiDE India)
- Janelle Robinson (STRiDE Jamaica)
- Marissa Stubbs (STRiDE Jamaica)
- Priya Thomas (STRiDE India)

