Dementia and the psychological wellbeing of older people and their formal and informal carers

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Dementia in a global context

- An umbrella term
- Mainly affect older people
  - but not a normal part of ageing & can affect younger age groups
- Estimated to affect 50 million people
  - Projected to reach 82 M in 2030
  - Nearly 60% live in LMICs
  - Under-reporting in many LMICs
- Considerable physical, psychological, social & economic cost
Policy attention

WHO
- Human rights’ approach
- Dementia plan guide

UN Decade of Healthy Ageing & SDGs

Economic & societal cost

Impact on the individual and family
(informal carers)

Less attention on the paid workforce
Ageism, Social Norms & Isolation in the context of dementia

- Pre-existing & new perceptions
- Definitional challenges: what does ‘ageism’ mean in different contexts and settings?
  - Benevolent and hostile elements
- Operates at different levels: cognition, emotional & actions
- Different components: stereotyping; prejudice and discrimination
- Intersectionality: age, disability, gender, race etc.
The formal & informal spheres of care
Workforce training & development
LTC working conditions and workers’ wellbeing
  - Relationships and emotional work; personal & professional boundaries
Recruitment, retention & sustainability
Supporting informal carers
  - Care burden
Self-care
  - AI & Assistive technology
Care models and preferences
LTC eco-systems in LMIC

- Universal health coverage remains an aspiration
- LTC is in a policy blind-spot, for many reasons
  - Reliance on families (traditional hubs of care)
    - Within a context of dynamic changes in family structures, living arrangements ...
  - Environment & infrastructures
- Some recent national, regional and global policy attention
  - Narratives of intergenerational solidarity, families & ageing in place
- Limited LTC services
  - Primarily community based, NGOs and informal arrangements
- Lack of acknowledgment of caring burdens (provided mainly by women)
- Opportunities: population dividends & labour supply

Wellbeing & inequalities

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Strengthening responses to dementia in developing countries (STRiDE)

- Theory of Change (ToC)
- Dementia awareness & Stigma
- The cost of unpaid care
- Cost & data
- Models of Care
- Training & Building capacity
- Accessible evidence
- Impact, Knowledge exchange & engagement

https://stride-dementia.org

Funder: UKRI- GCRF led by M. Knapp; LSE
The Middle East and North Africa Research on Ageing Healthy (MENARAH) Network

- Focuses on healthy ageing including brain health & dementia
- A network of researchers, NGOs, policymakers and practice professionals
- Aims to
  - Evidence generation
  - Knowledge mobilisation
  - Raising awareness & engagement
  - Inform policy & practice development
    - LTC, dementia care & UHC

https://www.menarah.org

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Funder: UKRI- GCRF led by S Hussein
Developing Practical Online Tools

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https://www.facebook.com/Our-Elders-Health-104264887980919/
The impact of dementia

Context and broader health systems
- Fragilities of care systems
- (Un)availability of dementia-specific formal support
- Intersectionality of gender, class & socio-economic status

Support mechanisms

Societal norms
- Stigma
- Public awareness & attitudes

Individual’s experience
Perceptions of ageing in general & dementia in particular

Differentials by societal & individual factors
Variations in health and wellbeing at older age is not random

Fragilities of care systems

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Impact on individuals and families

Managing the disease and its consequences
- Access to & trust in medical support

Managing negative views & stigma
- Cultural context
- (lack of) control
- Doing it ‘alone’
  - Shame and embarrassment
  - Relating & interacting with others
- Self-stigma

Power relationships
- Abuse & neglect

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Medical and LTC pathways
- Multi disciplinary approach & coordination

The role of traditional healers (LMIC)
- Should be a recognized element of care pathways
- Community support

Public awareness & Media

Importance of building trust & good relationships
Determinants of dementia-related wellbeing

- Health & LTC Systems
- Socio-demographic factors
- Cultural & Physical Environment

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Key messages

- Cultural-sensitive and context-specific policy & strategic direction
  - Ensuring all stakeholders perspectives
- Recognising the impact of stigma in accessing care and wellbeing of individuals and their family carers
  - Public perception and awareness raising
- The burden of dementia care is multi-dimensional
  - Financial, emotional, social exclusion
- Intersectionality
  - Gender, social class, poverty
- Training for formal and informal carers
- Ageism, abuse & neglect
Thank you for Listening

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