The impact experienced by caregivers taking care of people with dementia in Ghana

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Aim: Raising awareness, eliminate stigma and create a dementia friendly society

Alzheimer's & Related Disorders Association of Ghana
Aging Sub-Saharan Africa

Percentage increases in the population aged 60 and over in Sub-Saharan African countries: 2005 to 2030 (U.S. Census Bureau, 2005)
Dementia in Ghana

• Individual consequences dementia
  – Dependency; need for care

• Caregiver stress

• Lack of formal mental care

• Role of family in Ghana
  – 88% elderly live with younger relatives (Prince et al., 2007)
  – Informal caregivers

• Low awareness and stigmatization
  – Accusation of witchcraft
Research question

- Increase older people
- Prevalence dementia on the rise
- Lack of awareness and stigma
- Increase informal caregivers
- Stress on families

What **stressors** do caregivers of people affected with dementia in Ghana experience, and what is the **impact** thereof on the caregivers’ health?
• Explorative qualitative study performing semi-structured interviews
• Included caregivers:
  – Family members
  – Care providers (got paid)
• 9 families interviewed in urban areas
• 23 caregivers in total
Stress process model *(Pearlin et al. 1990)*

**Background and context**
- Age, gender, religion, education, occupation, family composition, relation, attitudes and beliefs

**Primary stressors**
- Objective stressors
- Subjective stressors

**Secondary stressors**
- Role strains
- Intrapsychic strains

**Impact**
- Social health
- Physical health
- Mental health

**Mediators**
- Social support
- Coping strategies
Stressors

• **Primary stressors:**
  – Difficulty handling behavior:
    • wandering, anger
  – Difficulty taking care of daily activities
  – Role overload:
    • no time for self, deny own wellbeing
  – Relational deprivation:
    • family conflicts, denial, misunderstanding
Results

Stressors

• Secondary stressors
  – Employment and financial issues
    • Quit jobs
    • Expensive hospital visits and medication costs
  – Family issues
    • Backing out of siblings/relatives
Results

Social health impact

Not being able to go out
- “Yes, it is the only social thing. Sunday the whole morning we were at church. After church we talked to our friends and now it is no more there.” (Par. 1, Family member)

Feelings of isolation
- Loss of social contacts, 24/7 supervision, lack of family support

Positive impact
- “Oh my social network was perfect. In fact, people were visiting her and developed an interest in me. Also peers of her church developed a new interest in me and out of that I am now attending her church.” (Par. 15, Family member)
Results

Mental health impact

Anxiety
- “I am very worried especially when he goes out and is not coming back. I am always worried, it is not good.” (P.9, Family member)
- You know, she’ll be insulting me: ‘I will use something to tube you, if you don’t talk to me!’ (...) At times I fear she will take something to tube me.” (P.5, Family member)

Depression
- Feelings of sadness → mostly related to mourning rather than caregiving

Positive impact
- “When I think back there are many lessons I drew. I feel happy that I played a part. Wherever mama is I am sure she will always remember me and I know my husband will always be grateful for that.” (Par.21, Family member)
Results

Physical health impact

**Bodily pains and tiredness**
- “Sometimes you will have bodily pains, you try to get up, but you can’t even get up because it is very tiring and very stressful.” (P.3, Care provider)

**Positive impact**
- No positive impact
Results

Contextual factors

• Perception dementia
  “Madness”, “crazy”, “witchcraft”

• Knowledge about dementia low

Mediators

• Informational support
  – Training, books, leaflets, internet

• Emotional focused coping
  – Enjoy taking care: humor, dancing, singing
  – Receiving love, affection, salvation
Discussion

• Behavior issues most stressful
  – wandering around and anger
    • Colombo et al. 2011
    • Rolland et al. 2003

• Employment and financial issues
  ➔ higher caregiver stress
    • Bookwala & Schulz, 2000
    • Uwakwe et al. 2009

• Influence unawareness and stigma
  – Reason to keep person with dementia inside
    • Mwinituo & Mill, 2006 ➔ Ghanaian caregivers of AIDS patients
Discussion

Social health

– Isolation: not able to go out
– lack of family support: changing family dynamics
  • Collectivism → individualism

![Graph showing comparison of Individualism in Ghana and Netherlands]
Conclusion

- **High caregiver stress**
  - Primary stressors: handling behaviour
- **Influence on all aspects of health**
  - Mostly on social health

**What to do?**
- Main goal is to increase awareness
- Increase pressure on government to support mental health more
- Collaborate with interesting parties
- Sponsorship/funding
- Respond to changing needs

**Increase stressors**

- Low awareness and stigma
- Lack of formal mental and elderly care
- Changing society dynamics
Thank you for your attention!

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