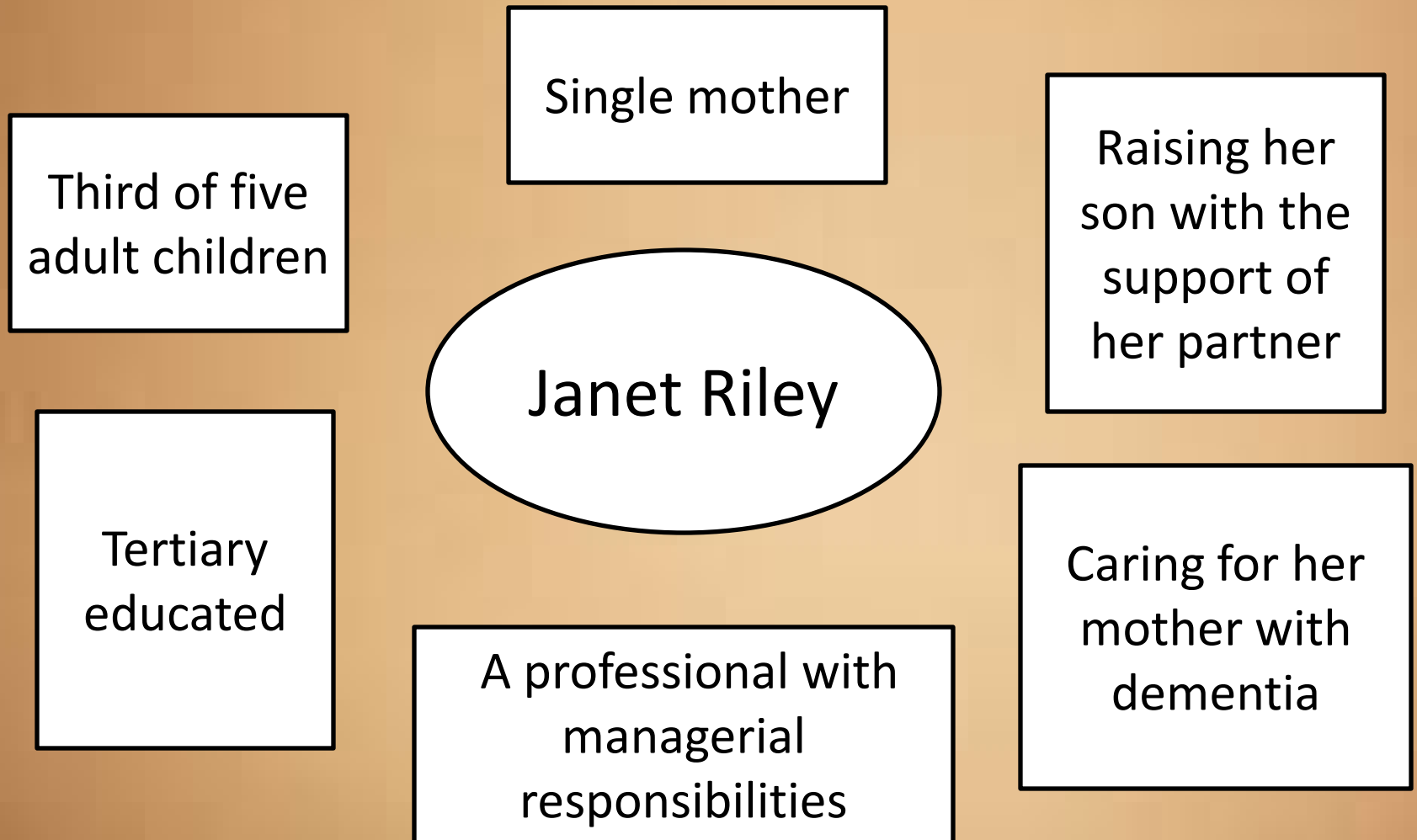




Unsilencing Dementia: Living, Working and Ageing with Dignity

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The Case



Themes

- Lack of understanding about Dementia
- The face of Dementia
- Sourcing and keeping a caregiver
- Costs of carework
- Negotiating work place relations
- Seeking Institutional Support
- Care at the home

Sourcing and keeping a caregiver

“He would go to Day-care and I had about two other persons who would help so either my sister would help or he would leave one Day-care to go to a next Day-care so it was like everyday somebody would handle until I get home... All these things costs money. Because the later I get home to pick him up, I had to pay extra for that and every time he goes by the baby”.

Household dynamics change

“Now she was hitting him... he didn't understand and things used to fall apart if I hit him. There was a day... there was a fight between her and him and he was disrespectful to her and then I realized that I really cannot leave them together because he's not understanding...I decided I had to get somebody to live in”.

“That had some issues because the house was a three bedroom but one of the bedrooms was used as a store room anyhow so it wasn't used as a bedroom... you give up your privacy; you give up so much when someone is living in your house right there”.

Cost of caring for an elder suffering from dementia

“When it started to take a physical and mental toll, I started looking at my siblings like what are y’all doing? Not only physical but money-wise...she also had health issues so I would have to check pressure, sugar, take her to clinic, she used to complain about back problem I used to take her to therapy”.

“There was instance where she had to go to a medical centre for a couple of days and it came up to \$8000.00. I paid it and then I was saying well right, I would get it back but they said she had reach her limit. So it was like ok, exhale, move forward, you gonna get more money”.

Emotional Cost

“This emotional thing of seeing her deteriorating and this thing of you having to be alert, you must be alert before she pick up a knife to cut herself, you always have to be peeping what she’s doing like we never rested. I started to get like nervous because you hype up all the time and then even when I leave and come to work, I would call and find out if she’s ok”.

Psychological Cost

“I would have to live with that if she gets away. Well I know they would blame me, although they not helping. We always have to have the lock on the gate and you know up to now I lock the gate every time... seeing her going down and you wonder if you did enough, if you doing enough, you guilty and then when I put her in the home, I had to seek counseling.”

Health Cost

“By that time I had high blood pressure, I had high cholesterol, diabetes, migraines and I was a mess, a total mess. But it is what I had to do [placing her in a home] and I’m now in a good place in terms of my health, all these conditions are now under control with medication but they’re still there. I feel better when I get up in the morning and I think because of that I had an early onset of menopause. So I also had to deal with the issues of menopause so I really was in a mess for a couple of years but I am in a good place now”.

Seeking Institutional Support

“I met some friends and they asked me about how my mom was and I said well she good but she not home now, she stays in a home and I saw the look on their face... like what? I knew once I walked away they would be bad talking me but so be it...I told my neighbours nothing”.

Care at the home

“They call her queen because she love nice clothes. I buy all kind of nice clothes and she’s always with her legs crossed, earrings and whatever, she’s dignified and I good. Rather than she was living alone and then you go, she have an old rip up something, the house dirty and that kind of thing”.

Dignity

“It doesn’t mean that the person must live alone, must stay in their home. It is about taking care of someone and they could eat, take medication. I see more about the person’s right than their dignity. Their right is to be comfortable. Their right is not to get lost on the street and you hear on the news that there was an old lady who went to throw out grass and they find her in some field”.

Interventions

- Cross- generational involvement in care work
- Changing strong cultural expectations that the family unit is the primary if not exclusive institution of care. There is need collaborative measures among family, friends and neighbours to meet the physical and affective needs of the elderly through a combination of resources.
- Social Centres to which relatives can carry their aged loved ones.
- Public awareness about ageing and attendant illnesses based on indepth research followed by public education and sensitization.

Dementia Villages



Thank You!