

The challenge of caring for incontinence: The experience of family caregivers of stroke survivors



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Purpose

 Understand the experience of caring for incontinence of family caregivers of older stroke survivors.

Methodology

- 1. A qualitative research design with in-depth interviews of the family .
- 2. Ten family caregivers of older stroke patients with incontinence were recruited.
- 3. Interviews were carried out with participants from different age groups and with differing relationships to the patient.

Result

Characteristics of the participants (n = 10)

Variable	No.
Gender	
Male	2
Female	8
Age	
20-40	4
41-64	3
65+	3
Relationship	
Spouse	2
Daughter/Son	4
Daughter or Son in law	2
Grandson/Granddaughter	2
Employment	
Yes	0
No	10

Characteristics of the patients (n = 10)

Variable	No.
Gender	
Male	5
Female	5
Age	
65-74	4
75-84	4
85+	2
Incontinence	
Only Urinary	3
Only Fecal	0
Dual	7
Barthel Index	
0-20 (total dependent)	9
61-90 (moderate dependent)	1

I needed to turn her left and right, while cleaning her up ...Washing and changing diapers,... lots of things to do...I was in a fuss and it's dirty everywhere

After the pooping she would unable to wait...I should be eager to quickly deal with the excrement and leave other things behind...other daily living care could be arranged and followed my schedule except the excrement...

Although I am a male, changing diapers skill cost lots of energy. Every time I finish the diaper-changing I feel my waist sour...

Diapers are more costly because I change them whenever she urinates and defecate...Good for her, I cannot save this money...I'm worried about money. These are really incredible costs on aids of dealing with incontinence

My daughter-in-law had cared elders and kids and was quite experienced. I did this (caring for incontinence) with her and learn how to deal with urinations and defecations ...Besides, I read and pay attention to food which are healthy, nutritious, and filled with fiber, which affects bowel movement. Now she defecates regularly and smoothly

Overall theme and subthemes

Theme/Sub-theme

Being in chaos

Fluster

Fluster

Fuss

I just thought that I should wear the gloves but it just happened so I was flustered and wanted to clean up all the mess as soon as possible possible.

Being in vigilance
Urgency
Health-hazard

Dirtiness

eing in exhaustion

Physical-consuming labor
Mental-consuming labor
Money/time-consuming labor

Being in creating a new life on trac

Learning from professions and accumulatin experience by doing Attitude adjustment and looking forward

I should change things immediately after he urinate or defecate, or else his bottom will flush and bleed and peel... I can feel his pain...If you miss once or twice, his skin will be injured and that will be an additional problem you have to deal with...

The uncontrollable pee and poo make the room smelly and

uncomfortable...dirtiness makes me feel upset and fluster

I will feel pressured and worry about whether I can handle this or not, whether she will be alright under my care or not...The invisible stress is huge

...I learned and now I feel I can almost handle it...Now I'm experienced at this and I feel the situation is not so hard anymore... I would no longer make poop everywhere...I do it smoothly now

If it is too hurry to wear gloves now, I just think that we are families so it doesn't matter...I can wash it later. It's all right and I am used to this situation... not feel flustered and fussy anymore

There is pressure, indeed, from taking care of her. But I would think the way that this is life. People get old and sick. What I can do is to give as much as I can so that I can say I did my best to myself. ...We should change ourselves and try not to, like before, think of sad and painful situations. We should think of the bright side of everything because that's the life we're given. We have nothing to do with it so the only way is to accept it.

Conclusion

- 1. A progress of mental reactions of family caregivers in caring for older stroke relatives with incontinence is proposed.
- Adjusting individual attitude toward a more positive, forward-looking process can help caregivers to build a bridge over their difficulties and keep on undertaking the tasks of care.
- Caregivers are eager to gain the technical support from health care professionals and the substantial financial support from government to help in recreating their new lives.
- 4.To assist health personnel in better supporting this vulnerable population meet their needs in caring for older stroke relatives with incontinence.

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