After a stroke, women described changes that created a sense of bodily strangeness

Kvigne K, Kirkevold M. Living with bodily strangeness: women's experiences of their changing and unpredictable body following a stroke. *Qual Health Res* 2003;13:1291–310.

Q What are women's experiences of their bodies after a stroke?

DESIGN

Giorgi's phenomenology.

SETTING

Hospitals and homes in rural eastern Norway.

PATIENTS

25 women (age range 37–78 y) who had been admitted to hospital with a first stroke, were able to participate in indepth interviews, and had no other serious disorders. 20 women completed the study.

METHODS

Women were interviewed 3 times: in hospital within 6 weeks of stroke, and at 6 months and 1 year after returning home. Conversational interviews that lasted about 1.5 hours focused on everyday life before stroke, thoughts and experiences related to the stroke event, experiences of bodily changes, experiences with healthcare professionals, and thoughts and wishes about the future. Interviews were tape recorded, transcribed, read to get a sense of the whole, and re-read to extract meaning units. Finally, themes and subthemes were generated.

MAIN FINDINGS

Women's descriptions of their bodily experiences after stroke wove together the past, the present, and the future. Stroke related changes created a sense of bodily strangeness expressed by 3 themes: *the unpredictable body*, *the demanding body*, and *the extended body*. The most fundamental change was that women's bodies became *unpredictable*, as evidenced by being *non-spontaneous* and requiring consciously thinking about and instructing their bodies in every action. Women also described their bodies as *vulnerable and defenceless*, disposed to complications and additional problems, or affected by normally innocuous situations, which led to despair, exhaustion, and interrupted rehabilitation goals. Many women felt that their bodies were *unreliable* and *betraying* them in performing normal functions.

The demanding body was *time consuming* in that it took longer to do activities and required training, therapy, and exercise to make it function. Women also described the *limiting* effect of their bodies on their activities, particularly because of extreme fatigue. They described their *dependence* on relatives, healthcare professionals, friends, and assistive devices, which reduced their freedom and flexibility. Women felt *conspicuous* because of their wheelchairs or

walkers, facial or limb paralysis, or lapses in memory when engaged in conversation.

The extended body encompassed all the helpers who, through assisting, became extensions of the women's bodies. Despite positive feelings toward helpers, women perceived help from unfamiliar people to be a strain.

CONCLUSIONS

Women's experiences of their bodies after stroke were characterised as the *unpredictable body*, *the demanding body*, and *the extended body*. The changes experienced were profound, disturbing, and unintelligible but also included a trend toward becoming familiar with, and adapting to, the changed body.

Commentary

Kvigne and Kirkevold provide powerful examples to illustrate that an understanding of women's bodily experiences before stroke and at the time of stroke is necessary to understand the post-stroke experience. Knowledge of women's bodily experiences after stroke is in turn an essential prerequisite to helping them to reintegrate and "re-own" their bodies.

Frameworks for the delivery of stroke services are often based on professionals' interpretation of recovery, which tends to be based on a biomedical perspective, rather than on what is relevant for individual patients.^{1,2} Although dialogue about participants' hopes and dreams for the future occurred, it was not explicitly reported. However, the implication is that strategies to help women incorporate and "re-own" their bodies and support them through the frustrations associated with achieving rehabilitation goals in their unpredictable, demanding, and extended bodies, need to be explored.

Although the authors compared meaning and changes over time, it would have been helpful to have a more thorough discussion of the timing of those changes to identify implications for rehabilitation services in the institutional setting and the home environment as suggested by Burton.² The only methodological concern is the lack of discussion around the rationale for selecting data sources and the recruitment and consent process.

The authors acknowledge that comparing the stroke experiences of women and men may have supported their reporting of the unique experiences of women. However, in their literature review and discussion, they substantiate the need for a feminist perspective to develop gender based knowledge.

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1 Bendz M. The first year of rehabilitation after a stroke—from two perspectives. *Scand J Caring Sci* 2003;17:215–22.

2 Burton CR. Living with stroke: a phenomenological study. *J Adv Nurs* 2000;32:301–9.

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