Parents of adult children with schizophrenia dealt with societal objections in order to provide the necessary care

**Design**
Grounded theory.

**Setting**
A private setting chosen by participants, usually their homes, in British Columbia, Canada.

**Participants**
29 parents (mean age 62 y) from 19 middle or working class families, many of whom were retired. Both parents in 10 families, mothers in 6 families, and fathers in 3 were interviewed. The parents had 6 daughters (mean age 30 y) and 14 sons (mean age 32 y). 2 offspring had died 5 years before the study. Parents had been caregiving for an average of 11.5 years.

**Methods**
1.5–2 hour indepth audi-taped interviews. All couples but 1 were interviewed separately. Interviews were transcribed verbatim. Theoretical saturation occurred after 32 interviews (total of 53 h).

**Main findings**
Parents of adult children with schizophrenia engaged in redefining their parental identity in order to adapt their caregiving to societal objections. This basic social process comprised 7 stages. Parent of a teen or young adult. Parents described their children’s early development as normal, without any indication of impending mental illness. None was overly surprised when behaviour deteriorated during adolescence, and only 2 parents suspected that antisocial attributes were indicators of mental health problems. Eventually, all parents realised that their children’s conduct was not normal. Becoming marginalised involved becoming alarmed and assuming responsibility for the child, but also encountering barriers. Children became excessively angry, depressed, anxious, isolated, or preoccupied, and family relationships suffered. Once a child was diagnosed, parents found that their influence was severely limited. Marginalised parents saw themselves as disenfranchised. The disenfranchised parent. Parents continuously met obstructions when they tried to intercede on their child’s behalf. The stage was characterised as a miserable existence of maintaining vigilance, grieving alone, and grasping at straws. Embracing the collective. By connecting with others, parents learnt that they no longer shared a common problem. They communicated with each other and shared strategic approaches. The re-enfranchised parent. Parents regained their rights and responsibilities by taking on the “system” through volunteer work, advocating for patients with mental illness, and providing public education about schizophrenia. After many years and the achievement of some benefits for their children, parents began to reassess how they wished to spend their remaining years. Evaluating my life. Parents acknowledged realities and identified personal needs. They focused more on themselves or long ignored interests and moved towards mutual independence between themselves and their ill child. The emancipated parent.

Although the lives of all parents and their ill children improved, mutual independence was an unattainable goal. The end point was a hybrid identity combining (in varying degrees) the re-enfranchised parent and movement toward emancipation.

**Conclusion**
After feeling marginalised and disenfranchised, parents of adult children with schizophrenia adapted their parental care to societal objections through a basic social process involving 4 parental identities and 3 transitional states.

**COMMENTARY**

**QUESTION:** What is the subjective and emotional experience of parental caregiving in schizophrenia?

**Source of funding:** no external funding.

*For correspondence: Dr P J Milliken, School of Nursing, University of Victoria, Victoria, British Columbia, Canada, jmilliken@uvic.ca*