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| **­­­Title** | |
| **Abendroth M, Lutz BJ, Young ME.** Family caregivers’ decision process to institutionalize persons with Parkinson's disease: A grounded theory study. International Journal of Nursing Studies. 2012;49(4):445-54. | |
| **Agreement** | **309/1619** |
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| *The whole day was surrounded by medication timing, by therapy, by exercising, by naps, by food choices that don’t interact with the medicine. . . Yeah, if she takes the medicine at 8:00, then we can schedule a doctor’s appointment for 9:00, because the tremors will be over,and we can be dressed. If we can get back by 11:00, then we can take medicine at home. So, that half hour or so*  *that she’s going to be tremoring so badly, she’s here and she’s comfortable. Then we can have lunch, and then if we want to go out, we have this window of time*. *Qcarer*  Availability of support structures was an important condition that impacted strain. Formal and informal support were important to overall caregiver well-being, especially in reducing strain in order to help them better manage caregiving responsibilities. The findings showed that support, individualized for each family, had many intertwined facets. For example, friends provided needed empathy that some families were unable to provide, whereas health care providers provided specific services (e.g., nursing care, mental health counseling and community referrals to support groups and respite care).  *Respite would help because I know I’ve tried it before and my attitude changed during that time. Actually I felt more rested and felt like I could cope better. When I was able to get away and do something on my own*. Qcarer  They were planning, seeking knowledge, making adjustments to the home environment, seeking support, and caring for self. Day-to-day planning became a priority due to the complex nature and unpredictability of symptoms of Parkinson’s disease progression. For example, planning focused on monitoring medication schedules due to the high frequency of dosing and to prevent other drug and food interactions. The strategy of seeking knowledge about the illness was also common in order to mitigate the anxiety of this type of complex caregiving. Caregivers also sought to learn about resources that could provide them respite opportunities.  *It was not just the Parkinson’s. It really mainly was the intestinal problems—the reason. I didn’t feel I could handle the intestinal thing and also the Parkinson’s. . .. that made me realize that I couldn’t anymore. Qcarer*  In this incident, there were numerous events that led to placement, and the worsening other health condition of this relative with Parkinson’s disease played a pivotal role in the caregiver becoming exhausted and unable to manage his care.  if a sudden serious illness affected the caregiver, the strain would be so severe that it could not be  moderated. A change in family finances due to lost retirement investments or other financial concerns was another life event that increased caregiver strain. Caregivers often found that financial crises, coupled with the rising cost of caregiving, made long-term care placement prohibitive. The following quote by a caregiver illustrated this concern.  *I think when people hear Parkinson’s, they think Michael J. Fox. They think Janet Reno. They think Pope John Paul, Mohammed Ali. The difference between those people and the reality of most Americans is that they have plenty of money to have the best care (including long-term facility care) and all the help in the world that they need, and 99% of Americans don’t have that. Qcarer* | |