|  |  |
| --- | --- |
| **Title** | |
| Giles S, Miyasaki J. Palliative stage Parkinson's disease: patient and family experiences of health-care services. Palliat Med. 2009;23(2):120-5. | |
| Agreement | 574/1046 |
| Final Agreement | 757/1046 |
| **Agreed** | |
| Participants discussed the lack of information received regarding prognosis, diagnosis, and homecare services, and not knowing or being able to ask for what was missing. Some had strong feelings that care should have been provided differently, and wished they had been given more information.  *“I didn’t get the brochures or anything from the doctors.”*  *“…there’s really not much there to help.”*  One person indicated that they did not know what to ask for and suggested that the health-care team should assume a specific educational role.  *“That [home care services] is something that you know somebody should tell those people.”*  Another participant hinted, how her sense of independence may have been a barrier to asking for home care services: “I never asked.” In the end, though she decided to “just give up” asking for physiotherapy services and decided to “get used to it”, suggesting that a sense of learned helplessness had finally been adopted by her as a coping strategy.  Another reason for not asking for more information appeared to be rooted in the inherent power imbalance between the doctors and the patients. While she wanted to know this information, she was reluctant to ask for it due to the fear of being reprimanded. She was concerned that they gave her spouse medication without telling her and him “what the side effects are”.  *“I’m the type of woman, I’m afraid to ask too many questions because sometimes I felt like they would say, like you’re asking too many questions, just take the pills”*  This power imbalance manifested itself in the form of not seeking health information based on the fear of being reprimanded by the doctor.  People gave up waiting for government funded homecare support and expended a great deal of effort trying to obtain private home care.  *“they (government homecare) still haven’t called us… so we’re lucky that, you know, we finally made the decision to move on. Because I don’t know what we would have done because I don’t think my mom would have lasted”*  It is difficult for families seeking private care to judge the quality of services offered:  *i: how many companies did you interview?*  *r: about 7*  *i: and how did you find them*  *r: phonebook*  *i: okay*  *r: which is also, like you know, I started going through the phonebook and choosing, you can’t judge a book by its cover and that is what I was doing, judging by their ads, and then like some of them would have these accreditation kind of things but I didn’t even know what they meant. So I was like, this one’s got three like little gold medal things so maybe I’ll go with this one and this one’s only got one I’m not gonna call them.*  One private home care company was problematic, “super expensive,” had staff who were not qualified, and it was difficult to work with them that in the end they gave up and finally found help through a friend.  *“And the people (private homecare) that they send are just, we went through a whole slew of people and they’re just not… like, I thought that some of the women weren’t even qualified. You shouldn’t be doing that work”*  Even finding a neurologist was challenging.  *“At this point, by fluke, a friend of ours, his brother died who passed away from cancer and he’s very well known in this hospital for helping out. I think he donated a lot of money and he’s best friends with my son-in-law. They were the best man at each others’ weddings, so when he heard what we were going through he offered to talk to us, for us, to see if a doctor could see my husband and that’s how we got our neurologist”.*  Due to a lack of information from their doctor, one family turned to the Internet for help. In the end, they were “shocked” and saw the Internet as unhelpful and a “mistake” and they decided that they would advise others to not repeat the same mistake.  *R: …I made the mistake of going online which I think is not always a good thing for caregivers because it always gives you the worst-case scenario. Or, it’s easier to find the worst-case scenario. So it was really shocking*  *I: wow*  *R: to read all that ugliness, um, because I mean I know you have to deal*  *I: yes*  *R: and you have to be prepared and understand. It’s just kind of a shocker and no one really explained to us what all this meant.* | |