Facilitators and barriers to the delivery of palliative care to patients with Parkinson's disease: a qualitative study of the perceptions and experiences of stakeholders using the socio-ecological model

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Abstract (300 word limit)

Statement of the Problem: Palliative care (PC) can improve the quality of life of Parkinson's disease (PD) patients and their carers, however, current research on the impact of the provision of PC services for patients with PD is still unclear. We sought to identify the barriers and facilitators affecting the provision of PC services for patients with PD based on Social Ecological Model (SEM) framework. Methods: We conducted semi-structured interviews and the SEM was used to organize themes and identify potential solutions across multiple levels. Results: Twenty-nine patients were interviewed. Facilitators and barriers were identified according to the levels of the SEM. There are 2 facilitators and The facilitators were as follows: (1) individual level: strong needs from PD patients and relatives, health professionals' desire for PC knowledge; (2) interpersonal level: social support; (3) organizational level: firmly attitudes towards the systematization of PC, a large team of nurses; (4) community level: convenience of community services, a Hospital-Community-Family-Based service; (5) culture and policy level: existing policy; while the barriers were: (1) individual level: false beliefs about palliative care, economic burden; (2) interpersonal level: lack of communication time, low quality of multidisciplinary teamwork; (3) organizational level: lack of PC specialist nurses, lack of referral criteria for PC, absence of economic benefits indicators; (4) community level: lack of PC resource access, discontinuity of care; (5) culture and policy level: culture of death, ethical dilemmas, lack of health insurance for PC. Conclusion: The application of a social ecological model in this study helped to illuminate the complex and multilevel factors that may influence the delivery of palliative care among PD patients.

Image



Figure 1 Palliative care facilitators for patients with Parkinson's disease



Figure 2 Palliative care barriers for patients with Parkinson's disease

Recent Publications (minimum 5)

1. Armstrong, M. J., & Okun, M. S. (2020). Diagnosis and Treatment of Parkinson Disease: A Review. Jama, 323(6), 548-560.
2. Boersma, I., Jones, J., Coughlan, C., Carter, J., Bekelman, D., Miyasaki, J., . . . Kluger, B. (2017). Palliative Care and Parkinson's Disease: Caregiver Perspectives. J Palliat Med, 20(9), 930-938.
3. Bouça-Machado, R., Titova, N., Chaudhuri, K. R., Bloem, B. R., & Ferreira, J. J. (2017). Palliative Care for Patients and Families With Parkinson's Disease. Int Rev Neurobiol, 132, 475-509.
4. Room R, BaborT, Rehm J (2005) Alcohol and public health. Lancet 365: 519-530.
5. Sullivan EV, Zahr NM (2008) Neuroinflammation as a neurotoxic mechanism in alcoholism: Commentary on "Increased MCP- 1 and microglia in various regions of human alcoholic brain". Experimental neurology 213:10-17.

Photograph



Biography (150 word limit)

Dr Chen has her expertise in improving and promoting the palliative care in Parkinson's disease. She focuses not only on people with Parkinson's disease, but also on the caregiving burden of their carers, developing a corresponding theoretical model of caregiving burden. Dr Chan is committed to promoting clinical practice through the integration and mining of evidence, and specialises in qualitative research methods to uncover the barriers and facilitators behind palliative care from a constructivist perspective.

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