Parkinsonism and Related Disorders 15S3 (2009) S118–S121

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Who cares for the caregiver?

Carmen Dyck*

Registered Clinical Counselor, Former Director of Education and Support Programs, Parkinson Society British Columbia, Canada

ARTICLE INFO

Keywords:
caregiver
skills
Parkinson's Disease

SUMMARY

A confluence of variables in Parkinson's disease results in Parkinson's informal caregivers facing tremendous challenges. Factors include: motor and non-motor symptoms, staging, rate of progression and increased life expectancy of people with Parkinson's (PwP) due to effective drug therapy and surgery. Informal caregivers may have to cope with dispersed family members, and a lack of centralized disease specific healthcare support alongside shrinking healthcare budgets and resources.

These variables demonstrate the need to strategically address the unmet needs of the informal caregiver. Expectations placed on caregivers by themselves, the PwP, family members (often absent) and the healthcare system can threaten their physical and mental health, giving rise to the question: Who cares for the caregiver?

In answering this question, this article discusses the needs of caregivers, presents various models of caregiving, and considers the nature of caregiver interventions.

1. The caregiving context

Parkinson's disease (PD) is a progressive, chronic illness, often of long duration; informal caregivers face the challenge of having to make continuous adjustments to their lives as they care for someone with this complex illness. Many, if not most, caregivers struggle to cope with the various expressions of PD with its variety of motor and non-motor symptoms. At diagnosis, caregivers are faced with an uncertain future with regard to progression, making it extremely difficult to learn how to cope with a condition that has such a variable prognosis.

As PD progresses, caregivers adapt to a role for which there are no rules and which challenges them on a daily basis; caregivers provide help to someone whose mobility may fluctuate so that at times little help may be required, while at other times, the PwP may be almost completely dependent on others for care. The caregiving situation can become even more complex when end of life issues have to be faced, where caregivers encounter the ever increasing needs of a PwP in the face of limited services. Given the nature of the PD spectrum, the caregiving role usually unfolds slowly but over a long period of time.

In some senses, this is an unprecedented time for both PD informal caregivers and healthcare providers. The treatment of PD was revolutionized in the late 1960s, and as effective treatment was discovered, its impact was remarkable with regard to both duration and quality of life for PwP and their caregivers [1–3]. Concurrently, advances in both medical care and public health, including enhanced access to immunization, drug therapy sanitation, and nutrition have resulted in larger numbers of people living longer, and thus, at risk for more health problems [4]. Additionally, the lengthened lifespan of PwP has increased the need for, and use of, services.

When caregivers cannot cope with the demands of caring for a PwP, the burden may shift to the healthcare system. This question, "Who cares for the caregiver?" becomes even more urgent given the incoming "demographic imperative", where numbers of adults over age 65 in the U.S. (and other countries) are expected to double in the next twenty years [5]. Yet caregivers seeking help encounter barriers as they attempt to access overextended healthcare systems whose foundations are cracking [6], resulting in the reduction of services. Medical and social gains, including the demise of the nuclear family, more women in the work force, delays in retirement, and increased life expectation, result in increasing numbers of older adults needing care with fewer family members at home to provide it [7]. The case is clear – caring for the caregiver is crucial, not only for what they provide and the resultant effects on PwP and society at large, but simply due to the fact that they are human beings in need of assistance.

2. Needs and challenges faced by caregivers

Clearly, PD is a complex disorder, and the difficulties faced by caregivers often depend on the nature of the progression. Its motor features, including impact on general mobility, gait, falls, and motor fluctuations can certainly play a role in the need for caregivers to provide assistance. Caregivers may experience burden related to the PwP's activities of daily living, motor difficulties and levels of disability [8–12]. That said, non-motor symptoms, including sleep

---

*Correspondence: Carmen Dyck, MC.
E-mail address: carmendueck@me.com (C. Dyck)

issues, incontinence, depression and other mood disturbances, and cognitive changes, may be even more distressing for the caregiver and their quality of life [8,10,11,13–17].

Caregivers do not only face the present challenges of PD but may also experience extreme worry as they consider the future, wondering how they will cope with advancing PD and its accompanying prospect of profound deterioration [18]. Caregivers often feel overwhelmed, and may be grieving multiple losses as they reflect on the changes PD has introduced in their past, present and future.

3. Models of caregiving career and roles

The picture painted so far is quite grim. However, as healthcare professionals will know, some people can be remarkably resilient in the face of great difficulty, while others find it difficult to cope at all; this may have something to do with pre-morbid personality [19]. Healthcare professionals are privileged to have an influential role as they interact with people in need; however, this experience can be negative, neutral or positive, depending upon many factors.

One such factor influencing the interaction with caregivers is the health professional's understanding of caregiving. When counseling caregivers, using a conceptual framework of caregiving tasks may be useful, understanding that the experience of each stage will differ for each individual. The concept of a caregiving career has found support in the literature [20–22] This career is comprised of three general stages: first, the preparation for and acquirement of the caregiving role; second, the actual provision of caregiving and third, the disengagement from the role [20].

Caregivers and professionals may find it useful to understand further distinctions in this caregiving career. Montgomery and Koslowski propose seven markers to the caregiving career that further detail the actual tasks [21]. Naturally, they vary by situation and context, yet these markers can help to orient caregivers even when the nature of the disease process is uncertain. In order of succession, they are as follows:
Marker 1: Performing caregiving tasks
Marker 2: Self-definition as a caregiver
Marker 3: Performing personal care
Marker 4: Seeking assistance and formal service use
Marker 5: Consideration of nursing home placement
Marker 6: Institutionalization
Marker 7: Termination of the caregiving role

Each of these markers requires skill in order to learn the role and to manage the challenges that accompany them. Schumacher et al. make reference to “family caregiving skills” which share three characteristics [23]. First, caregiving requires combining previously learned skills with new ones specific to the care of the illness. Second, it blends knowledge of the person with information on the particular aspects of care required. Third, caregiving aptitude develops over time. Within this caregiving skill, there are nine core processes: monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system [23].

While providing caregivers with characteristics and models about the staging of both PD and the caregiving career may help orient caregivers to the nature of their role, these models are not enough. Caregivers often feel powerless in the face of PD. It is important to acknowledge this and to recognize that there are no easy answers to the obstacles they may face.

In addition to this acknowledgement, it may also be appropriate to provide models for action. In the author's experience it is useful to talk with full time informal caregivers about the fact that they too “have” PD, that while they do not have the physical symptoms, they need to become accustomed to the fact that they are now living with the ramifications of PD on a daily basis. To do so, a framework of action could be shared with caregivers to help them understand the various tasks they faced. Known as the Chronic Disease Self-Management Program (CDSMP), books and education sessions teach patients and caregivers about the following tasks of managing a chronic condition [24].

1. Skills needed to take care of the chronic condition (such as taking medicines, exercising, doctor's appointments, accurately communicating symptoms, adjusting diet, etc.).
2. Skills needed to carry out normal activities (household management, employment, social life, etc.).
3. Skills needed to deal with emotional changes (those brought about by illness, such as anger, depression, uncertainty about the future, new expectations and goals, and adjustments in relationships).

The proportion of time spent on each task can vary according to disease stage and the personal, social and systemic resources of each caregiver, but these three areas are important to address at all times. Conditions like PD often require caregivers to learn new skills, or to adapt a previously existing skill set in order to better manage PD. The CDSMP also includes teaching on goal setting and action plans, a useful ability for caregivers as they become self-managers of their situation.

4. Assessment

When considering the topic of caregiving, there is always a danger that one will begin to think of caregivers as one homogenous group and assume that all caregivers respond similarly to the challenges of PD. This is clearly untrue! It takes only a few interactions with caregivers to realize that while there are many similarities in experience, each person's situation is unique. Thus, it is extremely important that healthcare professionals take the time to understand the situation of the caregiver(s) who sit before them.

While the healthcare professional has much expertise to share, it is wise to first assess the needs, level of known information and expertise of the caregiver. The following recommended domains and constructs of caregiver assessment were created by the Family Caregiver Alliance and are provided by the National Guideline Clearinghouse [25].

- Context (i.e. nature of the caregiving relationship, financial status, physical environment)
- Caregiver's perception of health and functional status of care recipient (i.e. consider biopsychosocial variables)
- Caregiver values and preferences (i.e. willingness to provide care, cultural norms)
- Well-being of the caregiver
- Consequences of caregiving (i.e. perceived challenges and benefits)
- Skills/abilities/knowledge to provide care recipient with needed care
- Potential resources that caregiver could choose to use

When it comes to assessment and planning, another important element to consider is the role of advance care planning for both the person with PD and the caregiver. It is easy to slip into a mindset where professionals assume that the health of a person with PD will decline more quickly than the caregiver. As this is not always the case, it is best to begin such discussions relatively early on (and over time as the disease progresses), as opposed to waiting until there is marked deterioration or crisis [26].

All the components of this assessment will assist the healthcare professional to understand the situation of the PwP and the caregiver better, ultimately resulting in improved healthcare and life planning.

5. Interventions and opportunities

In this author's experience, caregivers' needs center around two areas: information and support. Much research has examined the nature of caregiver interventions, yet many researchers commonly conclude that there is a dearth of solidly designed caregiver research studies [27,28]. In fact, one review evaluated several decades of research and concluded that "no available summary of effective interventions for carers and [their] unique support needs exists," and even more surprisingly, that little evidence supports both the general effectiveness and cost effectiveness of caregiver interventions [28].

With regard to caregiving research design problems, four have been noted by Zarit and Femia, including the mismatch of research design and treatment goals, the divergence between treatment and the actual needs of caregivers, the clarification of caregivers' goals (distinguished from those of the researcher), and the fact that few studies take into account the differences of caregivers' social roles and characteristics (gender, familial relationships, obligations, commitments, socioeconomic status, etc.) [29]. Alongside these findings, Zarit and Femia also discovered four overlapping qualities of effective interventions: a psychoeducational or psychotherapeutic approach (as opposed to pure education); multidimensionality (considering multiple factors relating to caregiving stress); flexibility, and sufficiency in the quantity and dosage of treatment.

However, even after considering the various models and research findings, when all is said and done, the question, "Who cares for the caregiver?" is still present. The answer is that each professional carries a certain responsibility. Without question, the nature and extent of this responsibility depends on one's role. However, in order for a PwP to live well, the caregiver also needs to be considered as part of the treatment unit, not simply as a resource to be plumbed in the answering of symptom assessment questions.

In some cases, caring for the caregiver may simply involve asking the question, "How are you coping with all of this?" and then listening, and depending on the answer, possibly making the appropriate referrals to other members of the healthcare team or wider healthcare systems. Such encounters can be challenging, especially when caregivers seek answers for questions that have no clear answer.

Even when detailed answers are not possible, healthcare professionals still have an opportunity to provide care and reassurance. Nurses and social workers often have increased chances to assist the caregiver in managing uncertainty. In the case of discussions around the rate of deterioration, there can be clear messaging to caregivers and PwP, with messages such as, "We don't know how your PD situation will progress, but we will assist you in every way possible as it unfolds." Such statements also carry responsibility with them. One must speak truth to caregivers, and so it behooves each centre and PD specialist to examine their own system of support for PwP and their caregiver so that they do not create expectations for care that cannot be met.

In this author's experience of speaking with informal caregivers across Canada, many were frustrated that there were not the same extensive resources for PD as there are for acute conditions. Conversations with PD specific healthcare and support professionals across Canada and the US expressed similar themes: that the needs brought forward by PD far exceed available resources.

Therefore, considering the question, "Who cares for the caregiver?" brings both challenge and opportunity. The question may become, "How can we help to care for the caregiver?" PD care centers may engage in a dialogue around these queries, considering: "What kind of support do we offer to caregivers? What difficulties do we face in the provision of this support? When we have been able to provide helpful assistance to caregivers, what did this look like? What factors (i.e. information, personnel, structured processes) made this possible?" Sometimes simple interventions can make a profound difference. Teams may ask themselves: "What questions are caregivers always asking us and how do we answer them?" and then compile a standard set of resources for caregivers.

Questions that consider the long term must also be considered, like "Is this type of outreach sustainable, and if not, what kind of systemic changes must be made? When does outreach to caregivers need to be PD specific, and when might existing generic caregiver resources be utilized?" Given the few resources that exist, it is important that they are used strategically. It must be clearly stated that PD professionals cannot meet all the needs that are presented to them, and so caregiver interventions must always consider how to make use of community resources. It is important to help caregivers begin building their circles of support from the time of diagnosis, given that the journey can be very long and difficult.

While there are mixed findings in the research on various psychosocial interventions, it cannot be disputed that most people benefit from speaking with someone who has a sense of their experiences. In fact, one of the most important things a professional may do is link one caregiver with another, where stories can be shared and challenges can be discussed. Time and time again, caregivers speak to the value of knowing that they are not alone, that others have similar experiences and that they have found ways to cope.

6. Conclusion

It is important for professionals to remember that they assist PwP and their families on a journey they have never taken before. While healthcare professionals may have accompanied thousands of people along the way, helping them to interpret the various paths and travel options, and it is easy to forget that not everyone knows what to do in the face of the many challenges associated with Parkinson's.

Caregiving for a person with Parkinson's can be difficult. Healthcare professionals have many opportunities to assist caregivers as they seek to understand their role. Who cares for the caregiver? We all must.

Acknowledgements

Special thanks to Susan Calne for her editorial help. The author would also like to thank the thousands of caregivers she interacted with during her time at Parkinson Society British Columbia for teaching her about the challenges and opportunities in caring for a person with PD.

Conflict of interests

None declared.

References

1. Cotzias GC, Papavasiliou PS, Gellene R. L-dopa in Parkinson's syndrome. N Engl J Med 1969;281(5):272.
2. Hoehn MM, Yahr MD. Parkinsonism: onset, progression, and mortality. Neurology 1967;17:427–42.
3. Rajput AH. Levodopa prolongs life expectancy and is non-toxic to substantia nigra. Parkinsonism Relat Disord 2001;8(2):95–100.
4. Maier K, Calne SM. Informal Caregiving: A valuable part of the health care team. In: Ebadi M, Pfeiffer RF, editors. Parkinson's disease. Boca Raton, FL: CRC Press, 2005. p. 999–1008.
5. Jurowski E.T. Policy and program planning for older adults: realities and visions. New York: Springer, 2008.
6. Canadian Public Health Association. The future of public health in Canada. 2001. [Available at http://www.cpha.ca/uploads/policy/Future_e.pdf].
7. McClure Cassie K, Sanders S. Familial caregivers of older adults. J Gerontol Social Work 2008;50(3):293–320.

8. Cifu DX, Carne W, Brown R, Pegg P, Ong J, Qutubuddin A, et al. Caregiver distress in parkinsonism. J Rehabil Res Dev 2006;43(4):499–508.
9. Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with Parkinson's disease. J Neurosci Nurs 2002;34(4):184–90.
10. Martinez-Martin P, Forjaz MJ, Frades-Payo B, Rusinol AB, Fernandez-Garcia JM, Benito-Leon J, et al. Caregiver burden in Parkinson's disease. Mov Disord 2007; 22(7):924–31.
11. Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. Parkinsonism Relat Disord 2006;12(1):35–41.
12. Caap-Ahlgren M, Dehlin O. Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. Aging Clin Exp Res 2002;14(5):371–7.
13. Given B, Sherwood PR, Given CW. What knowledge and skills do caregivers need? Am J Nurs 2008;108(9 Suppl):28–34.
14. Goldsworthy B, Knowles S. Caregiving for Parkinson's disease patients: an exploration of a stress-appraisal model for quality of life and burden. J Gerontol B Psychol Sci Soc Sci 2008;63(6):372–36.
15. Miller E, Berrios GE, Politynska BE. Caring for a person with Parkinson's disease. Int J Geriatr Psychiatry 1998;11(3):263–8.
16. Pal PK, Thennarasu K, Fleming J, Schulzer M, Brown T, Calne SM. Nocturnal sleep disturbances and daytime dysfunction in patients with Parkinson's disease and in their caregivers. Parkinsonism Relat Disord 2004;10(3):157–68.
17. Thommessen B, Aarsland D, Braekhus A, Oksengaard AR, Engedal K, Laake K. The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. Int J Geriatr Psychiatry 2002;17(1):78–84.
18. Hudson PL, Toye C, Kristjanson LJ. Would people with Parkinson's disease benefit from palliative care? Palliat Med 2006;20(2):87–94.
19. Hooker K, Monahan DJ, Bowman SR, Frazier LD, Shifren K. Personality counts for a lot: predictors of mental and physical health of spouse caregivers in two disease groups. J Gerontol B Psychol Sci Soc Sci 1998;53(2):73–85.
20. Aneshensel CS, Pearly LI, Mullan JT, Zarit SU, Whitlach CJ. Profiles in caregiving: the unexpected career. San Diego, CA: Academic Press; 1995.
21. Montgomery RJV, Kosloski KD. Family caregiving change, continuity and diversity. In: Lawton MP, Rubenstein RL, editors, Interventions in dementia care: towards improving quality of life. New York: Springer; 2000. p. 143–71.
22. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. Gerontologist 1990;30(5):583–94.
23. Schumacher KL, Stewart BJ, Archbold PG, Dodd MJ, Dibble SL. Family caregiving skill: development of the concept. Res Nurs Health 2000;23(3):191–203.
24. Lorig K, Holman H, Sobel D, Laurent D, Gonzales V, Minor M, et al. Living a healthy life with chronic conditions: self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema & others, 2nd edn. Boulder, CO: Bull Publishing; 2000.
25. Family Caregiver Alliance. Caregiver assessment: principles, guidelines and strategies for change. Report from a national consensus development conference (Vol. I). San Francisco: Family Caregiver Alliance; 2006.
26. Bunting-Perry LK. Palliative care in Parkinson's disease: implications for neuroscience nursing. J Neurosci Nurs 2006;38(2):106–13.
27. Zarit SH. Do we need another "stress and caregiving" study? Gerontologist 1989; 29(2):147–8.
28. Hempel S, Norman G, Golder S, Aguiar-Ibanez R, Eastwood A. Psychosocial interventions for non-professional carers of people with Parkinson's disease: a systematic scoping review. J Adv Nurs 2008;64(3):214–28.
29. Zarit S, Femia E. Behavioral and psychosocial interventions for family caregivers. Am J Nurs 2008;108(9 Suppl):47–53.