D.8 Palliative Care

Study details	Participants	Methods	Results	Comments
Full citation Kwak,J., Wallendal,M.S., Fritsch,T., Leo,G., Hyde,T., Advance care planning and proxy decision making for patients with advanced Parkinson disease, Southern Medical Journal.107 (3) (pp 178-185), 2014.Date of Publication: March 2014., 178-185, 2014 Country/ies where the study was carried out USA Study type cross-sectional survey Aim of the study to examine advance care directives and proxy decision making by family healthcare proxies for patients with advanced PD Study dates Published Sept 2013 Source of funding partnership and innovations grant program of Parkinson's research Institute of Wisconsin Parkinson association	Sample size N = 64 spouses and adult children of patients with PD Inclusion criteria Patient eligible to participate if patient was at least 60 years old, diagnosed with having ideopathic PD or parkinsonism for at least 5 years, diagnosed by a neurologist or movement disorders specialist consultant according to PD UK brain bank criteria. Patients considered to be at advanced stage of disease, which requires substantial caregiver involvement if the patients had dementia or scored <70% on Schwab and England ADL scale, indicating lack of full independence; >20 on UPDRS part II (functional impairment); or >40 on part III of UPDRS (motor impairments) family members eligible to participate if they were the patient's spouse/partner or adult child and designated healthcare proxy.	Details patients demographic and clinical data obtained from regional PD centre electronic patient register proxies provided info re education living arrangements and frequency of falls and general health of patient. proxies asked whether the patients had ever completed will or durable power of attorney for healthcare, and whether they had communicated to their physician preferences regarding CPR, ventilator, feeding tube, and hospice care proxies presented with hypothetical EOL scenario and asked to chosse a goal of care and treatment option if their relative with PD were in the situation. Initial scenario and EOL care goals and treatment choices adapted from theliteratures (Volandes et al,). reviewed and modified for patients with PD and palliation needs specific to this population. EOL scenarios described symptoms likely to occur in end-stage PD, i.e. dementia,	Results 70% proxies female patient mean age 75 yrs (6.8) mean UPDRS function 21.5 (7.6) mean UPDRS motor 31.1 (12.3) Schwab and England ADL score 53.4% (21.1) 31% diagnosed with dementia Advanced care planning - patients 60 (93.7%) completed will; 58 (90.6)%) shared copy with proxy; 24 (37.5%) shared copy with physician EOL treatments - patients 29 (45.3%) yes CPR, 13 (20.3%) DK; 13 (20.3%) Yes feed tube, 12 (18.8%) DK; 10 (15.6%) yes ventilator, 17 (26.6%) DK; 18 (28.1%) yes to hospice care, 46 (71.9) DK Goal of care, treatment, decision-making processes - proxies EOL care goal: 53% chose comfort care only; 38% limited care; 6% life-prolonging care treatment options: 72% pain and symptom control only;	**Overall serious risk of bias:** Methodology not clear, not clear whether all survey material was standardised or validated. **Other information:** Study only focuses on end of life care in advanced patients. NOTE: 30% of respondents had dementia diagnosis, which could skew preferences in current state from pre-dementia state and therefore not provide true representation of patient preferences from earlier stages of disease and pre-dementia manifestation.

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	Exclusion criteria none listed	inability to independently ambuilate etc Goal of care questionnaire included 3 options: life-prolonging care, limited care, and comfort only care Following goal of care questionnaire, proxies asked to choose among 3 sets of tmt options: perform everything that a modern hospital can offer; perform everything except for CPR or procedures used in ICU; and perform only procedures for pain and symptom control, but not hospitalization, CPR, feeding tube, ventilator, or other procedures common in ICU. Proxies also asked to choose from following options for how EOL decisions for patient should be made: one person decides alone, several people decide together, and several people talk, but one person makes final decision. Asked to indicate who should be involved in decision making Interventions data analysis: descriptive stats used to characterize patients' EOL preference, care preference, documentation and	16% chose everything except CPR or procedures in ICU; 9% chose performance of everything approx 70% chose treatment options consistent with goals of care. Proxy's EOL care choices for the patient were not generally consistent with patients choices for life support How should decisions for patients be made - proxy 53% several discuss but one person decides; 28% one person decides alone; 14% severl people decide together. 92% proxy should be involved; 72% other family members; 70% physicians should be involved; 52% think all 3 should be involved.	

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		communication, and proxy's choice of EOL care for patient		
Full citation Hasson,F., Kernohan,W.G., McLaughlin,M., Waldron,M., McLaughlin,D., Chambers,H., Cochrane,B., An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease, Palliative Medicine.24 (7) (pp 731-736), 2010.Date of Publication: October 2010., 731-736, 2010 Country/ies where the study was carried out Northern Ireland, UK Study type Qualitative: semi-structured interview Aim of the study to explore former carer's lived experiences of palliative and end of life care Study dates 2010 Source of funding Parkinson's disease society UK	Sample size N = 15 11 males, 4 females. age > 55 years Inclusion criteria Carers of someone with PD who had been bereaved between 6 months and 2 years. Had to be > 18 years of age, not chronically ill, and have no serious communication issues. All had been carers of someone with PD. all participants were immediate family members of the person they cared for. Exclusion criteria none listed	Details Exploratory descriptive design used. Qualitative semi-structured interview used to explore palliative and end of life care experiences of former carers of people with PD. Interview themes were: history of family members illness carers info and educational needs caring role impact on social, physical, and financial needs psychosocial impact of caring in the advanced stage spiritual support caregiving experience at advanced stage experiences of health and social services accessed experience of palliative care services accessed bereavement support accessed/needs Sensitive 1-1 interview conducted Participants recruited via poster in local GP and libraries, and PD support groups.	Results 4 themes identified: Carer's role and burden All spoke of gradual adjustment to carer role with adoption of multiple roles as disease progressed. Most provided care without any guidance from health professionals psychological impact of disease difficult: feeling of helplessness; lack of control; physical deterioration unpredictability of illness meant future plans could not be made many postponed their own needs ie. psych support, in order to meet patient's needs. carers found it difficult to deal with patients mood changes and anger and being physically and emotionally hurt by patient " there was one night he really, really was getting to me... i was going to life my hand at him. Thank God i didn't". Respite opportunities were viewed as essential to health and wellbeing of carer, however	Overall serious risk of bias: The study was retrospective and open to memory bias.

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		interview approach allowed for probing and clarification of responses, thus helping to ensure the correct understanding was obtained, All but one interview recorded and transcribed verbatim. Each interview subject to content analysis by 2 separate authors to allow for comparison and enhance inter-rater reliability. common and consistent themes drawn together in analysis Interventions N/A	accessing these was cited as very difficult. Palliative care watching physical and psychological deterioration of patient was most distressing to all caregivers most carers knew death was inevitable, there was an implicit aim of keeping the patient at home for as long as possible "Not that i was great at looking after him, but that's what I wanted to do anyway, I wanted him to be at home'. However this goal was prevented by a lack of access to domiciliary palliative care services such as hospice care. Few carers were fully aware of these services, with many viewing them as predominantly for patients with cancer at end of life. Some patients had died in hospital and nursing homes, not in own home. Many carers surprised at the speed at which advanced stage was reached and found patients' decline very sudden. They were unaware that death was imminent. Others wanted a quick painless death for the patient. Many spoke of	

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			feelings of relief at the patient's death, finding comfort that they were no longer suffering. All former carers advocated need to be better prepared for advancement of disease " I must say, I thank god he was taken that day". "I knew he was deteriorating but i didn't expect him to die so soon" " I feel maybe it's hard to say but i knew the end would come and really it was a release not only for me but for X, I knew it was because it was very hard to watch him" Bereavement note: not relevant to review question Access to health and social care services findings revealed access to palliative care and clinical services was uncoordinated and patchy, with carers explaining that they had accessed them on an ad-hoc basis. carers had to actively seek out info and access services on patient's behalf. All were frustrated that professional care was not in	

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			place for patients and carers at the start of the disease trajectory. In addition, some carers were confused over the boundaries and duties of the health and social care professionals involved. One carer recommended an MDT be established to deal with neurological illness "There seems to be a vague boundary between the responsibilities that one person has and the responsibilities another has. They just don't seem to work as a team or have any team effort as such. You are nearly taking pot luck with each one in turn" lack of signposting to services resulted in some patients not obtaining help from allied professionals such as physiotherapists, OT, or SLT, even though careres felt that this would have been beneficial. Carers spoke of MDT involved in care i//e/ PDNS, neurologist, GP. All appreciated support, however highlighted that accessing specialists was very difficult and lengthy waiting times.	

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			Quality of interaction between specialist, patient and carer was variable with meetings brief, focusing on medication, little or no psych support or signposting to other or no psychological support or signposting to other types of services. All carers advocated the need for regular surveillance of the patient's needs by specialists "the neurologist saw him every 6 months and agreed the tablets; they didn't have a lot of time. She (PDNS) would have helped explain things afterwards to you if you didn't pick it up at the consultation itself. Many carers relied on GP for help. some gave examples of lack of knowledge of the disease by GP's and social care professionals. All carers advocated need for adequately trained staff to care for PD patients. " The psychiatrist thought she was faking all her symptoms and that she hadn't PD at all, and took her off all of her medication" some felt lack of communication between primary and specialist health	

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			care providers with carer having to act as go-between " it was very frustrating because you were the liaison...you were at them to constantly go back and say this isn't working" All carers agreed should have been provided with a more integrated care package, regular access to specialist practitioner with clear signposting to other services and information. Carers wanted information to help them fulfil their caring role, with specific advice and training available.	
Full citation Kristjanson,L.J., Aoun,S.M., Oldham,L., 20061120, Palliative care and support for people with neurodegenerative conditions and their carers, International Journal of Palliative Nursing, 12, 368-377, 2006 Country/ies where the study was carried out Australia Study type Survey data	Sample size PD patient N = 174 PD carer N = 141 Inclusion criteria Self-administered questionnaires mailed to individuals with the 4 degenerative illnesses. Surveys distributed through the associations for these conditions. Exclusion criteria	Details service use and support needs component of survey developed using data from semi-structured interview with patients carers and HCP's. Interviews coded using content analysis to identify themes and these cross-references to the literature. data collection protocol designed to allow participants 30 mins to complete survey. patients and carers completed: demographic service use	Results >66% carers were female. mean age carers and patients 60 years 33% patients female. support needs and services patients and carers rated the amount of assistance needed to undertake several daily activities using Likert scale 1 (no help) - 4 (help needed all the time). Those items rated as >2.5 (leaning towards help most to all of the time) were:	Overall Risk of Bias: Serious. Methodology not clear, not clear whether all survey material was standardised or validated. Other information exclusion criteria that were imposed have determined the profile of disability and service use respondents - level of bias

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Aim of the study to identify and compare needs for supportive care/palliative care services of people in Australia with MND, MS, HD, and PD, and the needs of the carers. (NB only PD data presented here) Study dates conducted 2003 - published 2006 Source of funding National health and medical research council, Australia	Anyone who had recently been diagnosed or those who were too sick or disabled to answer.	support needs 2 item QoL index (Graham and Longham 1987) symptoms assessment scale (patients) hospital anxiety and depression scale (patients) patient satisfaction questionnaire (patients) general health questionnaire (carers FAMCARE scale (carers) content validity tested by pilot testing new protocol with 87 patients and carers internal consistency of instruments estimated using Cronbach's alpha. All had >0.70 high internal consistency Interventions NA	patients: information about disease (3.5); equipment for daily living (2.62) carers: information about how to provide care (3.31); reliable, ongoing, dependable support workers (2.84); financial assistance for care (2.72); flexible home support program access (2.52) QoL Asked to rate QoL on scale: 0 indicates very poor QoL to 10 - indicating excellent QoL PD patient rating of QoL = 6.87 (2.29; carer 6.59 (2.27) satisfaction with QoL patient 5.55 (2.68; carer 6.35 (2.58) Family satisfaction with care (FAMCARE): [5 point Likert scale] information giving 3.75 (0.74) physical patient care: 3.96 (0.70) psychosocial care : 3.70 (0.75) availability of care: 3.87 (0.67) HADS anxiety and depression 30% PD patients suffered moderate to severe depression; 20% anxiety	

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			Family carer's health score 19% carers experience overall dysfunction in anxiety and depression mean SAS symptom assessment scale for patient groups; highest scoring symptoms (i.e. >3.5): (0 = no problem, 10 = worst possible problem) fatigue and tiredness 5.1(2.9) concentration 3.9 (3.1) sleeping 4.1 (3.3)	
Full citation Giles,S., Miyasaki,J., Palliative stage Parkinson's disease: Patient and family experiences of health-care services, Palliative Medicine.23 (2) (pp 120-125), 2009.Date of Publication: 2009., 120-125, 2009 Country/ies where the study was carried out Canada Study type semi-structured in depth interview	Sample size N = 3 x family groupings ; total N = 7 (2 x carer patient 1; 2 x carer patient 3, and 3 x carer patient 2) Inclusion criteria participants received care at tertiary referral centre. Patients had been previously diagnosed with palliative stage PD (H&Y stage 2.5 - 5). Participants were purposefully selected by their neurologist for the	Details Analysis employed the interpretive phenomenological approach where the goal is to understand the meaning of the participant's experiences - relies on considerable self-reflection and interpretation skills of the researcher. Each interview read and reread in its entirety one interview at a time. Manuscripts then analysed as a unit together to reflect and maintain contextual aspects of their shared and divergent	Results Key themes: missing information lack of information received regarding prognosis, diagnosis, and homecare services, and not knowing or being able to ask for what is missing. Many wished they had been given more information " I didn't get the brochures or anything from the doctors... There's not really much help" " that (home care services) is	Overall Risk of Bias very poor study - very serious level of bias in terms of how participants were recruited, information was collected, interpreted, small sample size, and lack of detail in how information was interpreted. Text written in highly emotive and sensationalist way. Other information by study's own admission: methodology relies on

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Aim of the study to understand participant's lived health-care experiences and the needs flowing from them. Interviews followed the question: What are the lived experiences of the health-care system for persons and their family members, who have lived with the palliative stages of PD. Study dates 2009 Source of funding National Parkinson's foundation	ability to verbally discuss their experiences in detail. Exclusion criteria case 2 patient had sever dementia and could not participate, however his family were included in the study.	experiences. This allowed for comparison and/or contrast between interpretations of their experiences. Text interrogated and reflected upon to reveal deep and multiple meanings. During each interview clarification sought from participants to attempt to ensure correct meaning understood. Interviews recorded and then transcribed Interventions NA	something that you know somebody should tell those people" power imbalance between doctor and patient - "I'm the type of woman, I'm afraid to ask too many questions because sometimes I feel like they would say, like you're asking too many questions, just take the pills" Being on your own people gave up waiting for govt funded homecare support and expended a great deal of effort trying to obtain private home care "they (govt homecare) still haven't called us ... so we're lucky that, yuo 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" participants found it difficult to judge quality of homecare "I was like, this one's got three like little gold medal things so maybe I'll go with this one"... "super expensive" "and the people they send were just,	interpretation skills of the researcher.

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			we went through a whole slew of people" finding a neurologist was challenging: "a friend of ours... offered to talk (to a friend) for us, to see if a doctor could see my husband and that's how I got our neurologist" due to a lack of information, one family turned to the internet for help. they were "shocked" "you have to be prepared and understand it's just kind of a shocker and no one really explained to us what all of this meant" Patients and carers wanted a multidisciplinary (MDT) team to make care affordable, less time consuming, and credible. "that would be amazing if we didn't have to call 50 million different places and like try and figure out if they're able to do it and care for the people".. "for the clinicians to look at the whole person, not just questions about Parkinson's. To integrate the physiotherapy (into routine care)". wanting and not wanting A nurse caregiver was clear about roles that HCP should	

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			fulfil " to help the family or as a group decide what would be the best care situation for the person, and you know what to expect"	
Full citation Tuck,K.K., Brod,L., Nutt,J., Fromme,E.K., Preferences of patients with Parkinson's disease for communication about advanced care planning, American Journal of Hospice & Palliative Medicine, 32, 68-77, 2015 Country/ies where the study was carried out USA Study type Survey study Aim of the study To determine preferences of patients with PD for timing and initiation of discussions regarding treatment, prognosis, advanced care planning, and end-of-life care options such as hospice. Study dates Not reported	Sample size 267 out of 585 surveys were returned Inclusion criteria Age between 18 and 85 with a diagnosis of idiopathic PD confirmed by a movement disorders specialist Patients must have been visited at least twice in Oregon Health and Science University's Movement Disorders Clinic and must have received a diagnosis of PD at least 6 months prior to inclusion Patients could be in any stage of disease and be receiving any form of treatment Exclusion criteria - Patients with a known diagnosis of dementia, drug-induced parkinsonism, or atypical parkinsonism	Details Survey questions addressed patient preferences about prognostic and end-of-life discussions as well as basic demographic and disease-stage information. It also included the Patient Health Questionnaire Depression screen and the 7-item binary "information" subscale of the Krantz Health Opinion Survey to assess the degree that patients wished to be active in their own care. Interventions N/A	Results - Most patients felt responsible to bring up issues of life expectancy, end-of-life care planning, and end-of-life care options such as hospice. However, about half felt these topics should be raised by their neurologist. A very small number felt end-of-life issues should never be discussed. - Almost all patients wanted to discuss PD symptoms along with treatment goals, options, and side effects early (at the time of diagnosis or during the next few visits). The majority also wanted their family involved in discussing their disease early, and about half wanted to discuss advanced care documents early. Some patients even wanted early discussions about life expectancy, end-of-life care planning, end-of-life care options such as hospice or to encourage family communication about end- of-	Overall Risk of Bias: Likely high risk of bias Not clear whether the questionnaire was standardised or validated and lack of detail in how information was interpreted.

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Source of funding No funding received			life care, although it was more common for patients to want to discuss these issues when their disease worsened. - Majority of patients (183 of 267, 68.5%) reported having some kind of advance care planning document.	