

## 'Focus on the living before the dying': Advance care planning perspectives amongst those with Parkinson's Disease

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## Parkinson's Disease

- Parkinson's disease is a progressive, degenerative neurological condition which affects an estimated 70,000 people in Australia.
- Time from diagnosis to death is an estimated 12 years.
- After eight years an estimated 80% of people will have cognitive impairment.
- Care is more likely to occur in residential aged care facilities.
- Death is more likely to occur in hospital.

Giles & Miyazaki (2009), Tuck, Brod, Nutt & Fromme, (2015), Deloitte, (2014), Moens et al., (2015)

## Parkinson's Disease

- Communication problems: voice softness, huskiness or monotone, stuttering, slurring and rapid or slow speech patterns.
- Non verbal communication problems: masked-like expression, reduced blinking and limitations of body language.
- Uncertain disease trajectory: affects timing and initiation of conversations regarding planning for future health care needs.

Milner, et al., 2005; Pell & Monetta, 2008

## Advance Care Planning (ACP)

- ACP is an iterative process that involves a series of ongoing, reflective conversations.
- Future care decisions are based on a person's values and preferences should they be unable to decide or communicate those preferences due to limited speech or cognition.
- Preferences and wishes may be documented in an advance care plan and a surrogate decision maker appointed.

Singer, Robertson & Roy (1996)

## Advance Care Planning (ACP)

### Benefits:

- Improve end of life care
- Empower patients and families
- Improve quality of life
- Enhance feelings of control and hope
- Promote meaning
- Reduce suffering and foster dignity

Fraser Health Authority, 2007; Weiner & Cole, 2004

## And yet.....

- Uptake is low: estimated between 1 to 12.5% of the adult population in Australia.
- Emphasis is on completion of advance care plans rather than the conversations.
- Lack of evidence on the experiences of ACP in people with Parkinson's.

Hawkins & Cartwright, 2000; Seal, 2007; Scott, et al., 2013

## What we wanted to know

- How people living with Parkinson's, in the Australian Capital Territory, understand and experience ACP as their disease progresses from their own perspectives.

## Our approach

- Qualitative, exploratory study design.
- Purposive sample.
- 83 patients notes reviewed.
- After exclusion criteria applied 51 patients eligible.
- 20 consented to participate.
- Semi-structured interviews conducted.

## Framework for data interpretation

- Self determination theory (SDT): intrinsic and extrinsic motivators. Wellness when psychological needs met re: **competence, relatedness** and **autonomy**.
- SDT addresses **social** conditions which affect **individual** motivation.

Deci & Ryan, 2000

## Themes, subthemes and links between them



## Relatedness

- Personal relationships valued – individuals supported competence, choice making & the relatedness needs of others.
- Decisions re: future care - considered needs of others & related to social, legal reasons rather than for medical reasons.

## Relatedness:

### Legacy: Stories, funerals, Wills

-We have to write our life history for our daughter. I won't remember things...what happened here and there and the other thing I'm thinking is music/photos for the funeral day. Interesting when you think about ehm.....preparation for funeral and where you were born.....the children don't know where I was born..... (P7)

## Relatedness

- Identification - physical self **through** social action to create meaning, affirm values & direct them onwards in life & towards death.
- Deterioration - impact on sense of wellbeing & social activities.
- Participation - maintaining dance or travel motivating factors not the ability to exert choice and control over dying.

## Relatedness: Living: - Goal setting, Wellness, Social activities

"What keeps us together....my wife and I...is we used to dance a lot.....and I can't dance at the moment. Now that's a problem because that's our joint hobby". (P3).

"We want to focus on the living before the dying.....get back to exercising to improve my fitness and do some traveling". (P2).

## Relatedness

- Observing others – information internalised to reproduce or use to motivate self at a later stage in their own disease.
- Resourcing others – sought access to those they knew with Parkinson's.
- Witnessing others – deterioration, death or caring and learning from this to imagine their future.

## Relatedness: Learning from others

"Last year two close friends died....A third lives in a nursing home and I'll be following him very closely....as I guess that's a possibility for me" (P7).

## Relatedness: Learning from others

".....That woman (a friend) is looking after her husband who has Parkinson's and she is literally killing herself looking after him. He's terminal and very ill. ....but you know if I was like that.....I hope I'd be able to say put me where I can be cared for .....if I was the patient. This is the worry for me." (P8).

## Self mastery

- Rejection of sick role, with its expected norms and values (Varul, 2010) and with that the usual medicalised interpretation of ACP.
- Re-construction of ACP to suit needs and make choices accordingly.

## Self mastery

- "We read a lot and haven't been to the library. We went last week and it was a bit of a trial and tribulation. I used to walk around and pluck books from shelves. Last trip was hard. We'll need to look at different ways to get books.....get on the net.....see if I can get them to get books for me". (p3).

## Choice

- Clarity - purpose, content or location of documented ACPs lacking.
- Concerns - probability of documented preferences being fulfilled.
- Access - by which health professionals, when and how.

## Choice

"We've got wills....and living wills. All we have done is to incorporate in the will if we are terminally ill we don't want to be resuscitated..... I think it's linked to the will and power of attorney. I'm not sure how the will is worded given if I had a massive heart attack..... Do we need this if we go to hospital? I don't know if I'd give it to our GP...but to the hospital ...yes". (P2).

## Choice

"Last time I was in hospital, I went through advance care planning ...the minimum amount on the day so we didn't have to think about it in great detail. We went through it and then we stopped, so we didn't get far with it. I signed the papers. We thought it was wise to have it. We didn't question it. If there was any underlying factor, it was just that it would have been rude of me to go into hospital and not". (P7).

## Choice & Readiness

"I know I have to do it but it's getting there. Yeah....I think you've both got to be ready. No use her coming down in the morning and saying hey...get up!... cos we're going to talk about end of life. One or other may be ready but it needs to be both". (P7).

## Choice & The metaphorical bus

"There's no point in planning for what's going to happen. ...you could get hit by a bus.....you don't know what's going to happen...(laughs). We think it's all going to come good and the day before I die...right up until that time.....it'll all be good, ...(laughs) ...It might be partly burying my head in the sand and not wanting to think about it". (P3).

## Concluding.....

- Relatedness helped promote wellness, maintain social activities, foster social learning and affect decisions about EOL care beyond death which strongly links with authentic choice & self mastery.
- Experience of ACP included the broader context of life rather than the narrow focus of disease.

## Social death as a motivator

- Death of social self (Borgstrom, 2017) was more relevant to participants than planning for their biological death via ACP.
- Losses which individuals experience due to advancing disease need to be understood in the context of the individual's social life and not simply interpreted as a medicalised journey towards physical death.

## So what?

- Our participants' preference is for a tailored approach for ACP to meet individual needs with the focus being on living well rather than dying.
- Prevalent views amongst health professionals are that triggers, timing and content are important factors to consider in ACP for those with Parkinson's (Jackson, et al., 2014).

## Next Steps

- SDT offers scope for the person's social context to be considered and wellness promoted, even in the face of dying, rather than focusing on risk and deterioration as is usual in ACP.
- Further exploration of SDT as it relates to ACP is warranted.

## Next Steps

- Te Arai: Palliative Care and End of Life Care Research Group "Exploring motivations for, and experiences of, Advance Care Planning: a qualitative study".

## Thank you.....

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- Dr Aileen Collier – academic supervisor (ex-Flinders University & now lead investigator in NZ project)
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