

Research Profile:

Kim Jameson

Research Project:

Parkinson's disease patients', family caregivers', and clinicians' perspectives of advance care planning for end-of-life care.



Project Grant: \$105,000 over three years

Project Description:

End-of-Life Care Planning: Removing the onus from the patient

“There's a lot of uncertainty about when to initiate these end-of-life care discussions and when it is the most appropriate.”

When clinical ethicist Kim Jameson was interviewing patients for a project involving supportive decision-making, several people with Parkinson's disease raised the issue of end-of-life care. To Jameson's surprise, they told her neither their family doctors nor their neurologists had discussed planning for their long-term or end-of-life care. “Some talked about wanting to initiate these discussions with their clinicians to partner with them in planning for future end-of-life care needs,” Jameson says.

So Jameson decided to talk to more people with Parkinson's disease about their advance care planning needs. She plans to develop best practice guides to help doctors talk to their patients about these critical and sensitive issues, and to recommend ways to start the conversation. Jameson, a PhD candidate at the University of British Columbia, wants to find out what the barriers are that keep doctors from raising end-of-life care planning with their patients. She hopes her report will support health care professionals and the patients as they make these important decisions about medical intervention, pain management, artificial nutrition and hydration, and other end-of-life needs that align with people's values, beliefs and wishes. Having these conversations in advance, “can really help families and the patients themselves to relieve the stress and uncertainty they may have,” says Jameson. “The real outcome is to

generate patient-centred guidelines on how and when to engage people with Parkinson's disease and their caregivers in advance care planning.”

Jameson plans to publish her work in academic journals, and hold workshops and educational lunch sessions in healthcare settings to inform doctors and other health care providers about appropriate ways to engage their patients and begin these conversations. She hopes her research will relieve people with Parkinson's from feeling that the onus is on them to bring this difficult subject up with their doctors. Instead, she wants the health care professionals to feel comfortable and to have the right tools to initiate the conversations.

Jameson, who had family friends with Parkinson's disease, says that personal experience helps to inspire her to continue with her work. She hopes her guide will not only help people with Parkinson's disease and their doctors, but will also guide clinicians and patients who have other kinds of neurodegenerative diseases as well.

Biography:

Kim Jameson earned a Master of Arts in philosophy with a specialization in applied ethics from the University of British Columbia in 2009. Her Masters dissertation, supervised by Dr. Michael McDonald, focused on the ethical conduct of health research involving human subjects.

Jameson has worked as a graduate research assistant on a number of qualitative health research projects for over eight years and is currently working as a graduate research assistant on the ongoing CIHR funded project Supportive Decision Making for Diverse Populations. Jameson was an ethics fellow at Providence Health Care between September 2011 and May 2014, and is now working as a part-time clinical ethicist at Vancouver Coastal Health since August 2013. She has also been a volunteer ethicist on the UBC behavioural research ethics board since February 2014. She has published in top research ethics and qualitative methods journals and has delivered paper presentations at national and international conferences.

Jameson is currently undertaking her PhD studies in clinical ethics at the University of British Columbia's W. Maurice Young Centre for Applied Ethics under the direction of Drs. Anita Ho and Sally Thorne. In 2014, Jameson was awarded the Frederick Banting and Charles Best Canada Graduate Scholarship - Doctoral Research Award from the Canadian Institutes of Health Research through the Parkinson Society Canada. Her dissertation research project will focus on Parkinson's disease patients', family caregivers', and clinicians' perspectives of advance care planning for end-of-life care.