**Caregiving for the Caregiver Forum**

**Janet Powell, Ph.D., OTR/L,** *Associate Professor & Head of Division of Occupational Therapy* and

  **Hye Kyong Jeong, M.S.W.** *Director of Outreach & Advocacy, The Arc of King County*

Dr. Powell and her research team recently completed a study that used an educational and problem-solving approach to address concerns of caregivers of adults with traumatic brain injury (TBI). Dr. Powell and Hye Kyong Jeong, caregiver consultant for the study, presented the most common concerns faced by caregivers and the use of problem-solving strategies to address caregiver concerns with opportunity for open discussion.

Ms. Jeong explained that, in many situations, the caregiver is a family member, a close friend, or sometimes a neighbor. This role comes on suddenly and is life-changing. It is not a role that caregivers can prepare for with a a steep learning curve once the person with a TBI leaves the hospital. Ms. Jeong described how, as a caregiver, “Sometimes you feel like you weren’t given enough information, but also feel so overwhelmed by the information that you forget some of it once you bring the person with TBI home.”

Ms. Jeong described how isolation can be one of the issues that can arise for caregivers. Isolation typically comes after the intensive early period of hospitalization and treatment ends. Family and friends are there in the beginning, but over time, they go back to their lives, and the caregiver can be left to do the day-to-day care, often without help or a break. Ms. Jeong found herself not wanting to burden friends when they asked, “How are you?” “Do I say, ‘Fine.’ and move on, or do I ask, ‘How long do you have to talk?’” She also described how caregivers can feel like their situation is over-looked by providers whose focus is on the person with the injury.

Dr. Powell explained that previous research studies have found that 60-80% of caregivers had some degree of emotional distress and 25-30% had substantial depression. The current study also found that emotional adjustment was one of the top four concerns of caregivers along with figuring out how to get things done while providing care, engaging in healthful habits such as diet and exercise, and addressing emotional and behavior concerns of the TBI survivor. The study helped caregivers address these and other concerns through providing educational information and mentoring in problem-solving. Dr. Powell reported that the caregivers in the group that received the education and mentoring in problem-solving had lower levels of emotional distress than the control group. She described the advantages of dealing with concerns in real time and the problem-solving steps that caregivers in the study used to identify and implement solutions.

 The presentation was followed by an open discussion asking audience members for their advice on how better to support caregivers .

* Caregivers wanted to be more involved in care and decisions at the hospital and at follow up appointments. It would also be helpful if providers could talk to caregivers without the patient to give them an opportunity to share some of the things that the patient isn’t aware of.
* It would be helpful if the providers would ask the caregivers how they are doing
* There is still a gap of resources available to the caregiver to get the support that they need
* Suggestion was made to see if BIAWA could have a caregiver line- Idea will be brought to the TBI Council
* Past survivors are willing to help, knowing how difficult this can be
* Find ways to connect with your community and friends. Don’t be afraid to ask them to come over for a little while so you can go out, even for a few hours. Most people are more than willing to help than you may realize.
* Taking care of yourself will only help you to be more patient and able to handle things