17th Congress of the
International Society for Peritoneal Dialysis
VANCOUVER, CANADA | MAY 5-8, 2018

How should patient experience be better incorporated in PDI?

Allison Tong

Conflict of Interest

None to declare

“That there should be so much talk about what patients need and want without them being present prompted me to take action.” – Lucien Engelen

Patients Included journal charter clauses:

- At least two patients sit on the editorial board of the journal.
- Patients routinely publish editorials, reviews, or research articles in the journal as authors.
- Patients serve as peer reviewers of submissions to the journal.
- The journal is an open access publication, with no barriers to access full text content.

Why involve patients in journals?

- Publish what is relevant, meaningful and important to patients
- Align scope and content to address patient priorities
- Gain insights for patient-centred research, practice and policy
- Amplify the patient voice to the readership
- Empower patients

Currently in PDI

Experiences of Living with Assisted Peritoneal Dialysis – A Qualitative Study

Ingrid Petersson[1,2,3⇑] and Annette Lennerling[1,3]

Living with Encapsulating Peritoneal Sclerosis (EPS): The Patient's Perspective

Helen Hurst[1], Angela Summers[2], Kinta Beaver[3] and Ann-Louise Caress[4]

Patients' Perspectives on the Prevention and Treatment of Peritonitis in Peritoneal Dialysis: A Semi-Structured Interview Study

Denise J. Campbell[1,2⇑], Jonathan C. Craig[1,2], David W. Mudge[3], Fiona G. Brown[4], Germaine Wong[1] and Allison Tong[1,2]

More active involvement needed?

PARTNERING WITH PATIENTS

- Authors required to complete a **"patient involvement" statement**: setting the research question, outcome measures, design and implementation, dissemination
- Patient review of all relevant research papers, education and commentary articles (database of patients, patient advocates, caregivers)
- Co-production of educational/comment articles (e.g. editorials, analysis) with patients/caregivers + reviewed by patients
- Patients invited as sole authors for comment pieces, including editorials
- Monthly patient-led series "What your patient is thinking"
- Inviting submissions for the BMJ Opinion Patient Perspectives Series
- "Partnership in Practice" – illustrative example where patients and health professionals work together to co produce change in practice, education, research, and policy
- Appointment of patient/caregiver editors to bring the patient perspective to international discussion and decision-making bodies

WHAT YOUR PATIENT IS THINKING

"Where there is life, there is hope"

When Sarah Ezekiel received a diagnosis of motor neurone disease, she became deeply depressed. Seventeen years later, she describes what helped her regain hope

What you need to know

- MND can be unpredictable and everyone progresses differently
- Even with a terminal diagnosis, with the right support, people can feel better and even hopeful about their situation
- Early referral to hospice care and providing assistive technology can transform lives

Education into practice

- Do you know how to help your patients with speech or movement loss access assistive technology?
- Consider reviewing how many of your patients with terminal diagnoses have palliative care involvement, and who may require referral to your local hospice team
- Hope means different things to different people. How can you help your patients with terminal illness find hope in their situation?

BMJ Open

The PPI statement should appear at the end of the Methods section. It should answer the following questions:

- How was the development of the research question and outcome measures informed by patients' priorities, experience, and preferences?
- How did you involve patients in the design of this study?
- Were patients involved in the recruitment to and conduct of the study?
- How will the results be disseminated to study participants?
- For randomised controlled trials, was the burden of the intervention assessed by patients themselves?
- Patient advisers should also be thanked in the contributorship statement/acknowledgements.
- If patients were not involved, authors must state this.

CJASN: What's Behind and What's Ahead

Rajnish Mehrotra,[1] Michel Chonchol,[2] and Ian de Boer[1]

Clin J Am Soc Nephrol 13: 3, 2018. doi: https://doi.org/10.2215/CJN.13321117

We believe that the most important and innovative initiative at CJASN thus far is our attempt to incorporate the patient voice. The eventual goal of all biomedical research is to improve the health and wellbeing of patients. Therefore, the truest measure of value for every paper that we publish is its ultimate effect on patient care. Although biomedical journals have routinely solicited the opinions of other researchers on the work that they publish as editorials, most—including CJASN—have never solicited the opinion of patients.

- Patient Voice Editors: Paul Conway, Kevin Fowler, Lori Harwell
- Ask patients to write an editorial – patient's perspective on one article published every month
- Provide feedback to clinicians and researchers on the importance and limitations of nephrology research and what more needs to be done

PatientVoice

CJASN
Clinical Journal of American Society of Nephrology

Trust Patient Insights at Both the Individual and National Level

Paul T. Conway

As a newly appointed Patient Voice Editor for the *Clinical Journal of the American Society of Nephrology* (CJASN), I appreciate the unique decision of the CJASN leadership to elevate patients as contributors on their team. The strategy provides patients the opportunity to share practical health consumer perspectives along with experiential context to select journal articles. Also, for tens of thousands of patients with kidney disease, caregivers, and policy advocates who are not current readers of CJASN, they will now be able to read articles that accompany Patient Voice editorials, thus ensuring the growth of CJASN as a source of valued and shareable information across the patient community.

17th Congress of the
International Society for Peritoneal Dialysis
VANCOUVER, CANADA | MAY 5-8, 2018

PatientVoice

CJASN
Clinical Journal of American Society of Nephrology

An Evolving Continuum of Care for the Kidney Disease Patient Will Help the Transplant Center Patient Navigator

Richard A. Knight

Clin J Am Soc Nephrol 13: 519–520, 2018. doi: https://doi.org/10.2215/CJN.02300218

College of Business, Department of Management, Marketing, and Public Administration, Bowie State University, Bowie, Maryland

Correspondence:
Mr. Richard A. Knight, Bowie State

The article in this issue of the *Clinical Journal of the American Society of Nephrology* titled "Transplant center patient navigator and access to transplantation among high-risk population: A randomized, controlled trial" (1) represents a positive step in highlighting and overcoming existing barriers to kidney transplantation

patients who statistically fare the worst in obtaining a kidney transplant. Although the findings of the study indicated that the total effect on improving waitlisting of disadvantaged patients was relatively small and only observed after 500 days of follow-up, I do see value in further fine tuning the concept. One suggestion is to

17th Congress of the International Society for Peritoneal Dialysis
VANCOUVER, CANADA | MAY 5-8, 2018

Decision-making roles

- Patient-partners on the Editorial Board
- Patient reviewers

Patient/co-produced publications

- Patient editorials
- Patient voices articles
- Co-production of papers

Report patient involvement/experience

- Change authorship policies – statement on patient involvement/perspective
- Qualitative studies – reporting guidelines, call for patient perspective articles