



International Palliative Care Family-carer Research Collaboration

# Newsletter

September 2017

## Featured Member



**Yakubu Salifu**

IPCFRC Member

*Nurse Educator/ Registered Nurse (2nd Year PhD Nursing Student)*

*Nottingham Centre for the Advancement of Research into*

*Supportive, Palliative and End of Life Care (NCARE)*

*School of Health Sciences*

*The University of Nottingham*

*Nottingham, UK*

**Yakubu Salifu (RN, MPhil N, BSc N, Dip N, Dip Ed, FGCNM)** has been a nurse for over 11 years, mainly practising at the clinical setting and later teaching. He is a Foundation Fellow of Ghana College of Nurses and Midwives and a Member of European Association of Urology. During his role as a lecturer at Garden City University in Kumasi, Ghana, he served as the Coordinator for Nursing and Midwifery Council exams and students affairs, Secretary of Faculty of Health and Allied Sciences Board, a member of Faculty Research Committee, and Patron of Garden City University Nursing and Midwifery Students' Association. Yakubu's interest is in adult health nursing and advanced chronic diseases, home based care and quality of life.

### ***What are you currently researching?***

*I am researching on "Home-based supportive and palliative care for patients with Advanced-stage Prostate Cancer and their caregivers in a resource-limited sub-Saharan African country (Ghana)". I want to understand the experiences of patients and how family caregivers navigate their way through such care where the bulk and responsibility for such care is predominantly provided by families within the informal sector.*

### ***What inspires your research?***

*What motivates my research is the opportunity to get closer and understand patients' and caregivers' experience of living with and or giving care at home and what in their opinion might help them best. I am very much inspired by researchers, practitioners, educators, and advocates who are working to bring hope to patients and caregivers and I believe together we can make a difference.*

### ***How did you get into the palliative care field?***

*The upsurge in non-communicable diseases such as cancer has added a layer of complexity to the already limited health service demand and supply in developing countries. The inadequate support services for patients who may require special care or palliative care motivated me to do a PhD.*

*Continued...*

## Featured Member *continued...*

### ***In what way does your work benefit the community?***

*Home-based care is an economical and pragmatic means of care for patients who require palliative care in Ghana and since family caregivers are the 'General practitioners' of such patients at home, this research will be beneficial to signpost them to the best practices on how to care for patients in the home and community.*

### ***What is it that you enjoy most about your research?***

*Palliative care in Ghana is still at fledgling state and services are provided at few locations as institution-based outpatient care. I am passionate and glad to be among the pioneering generation of palliative care in Ghana that will advocate for such services to be closer to the doorstep of those who need it.*

### ***Tell us something that people might be interested to know about you?***

*I have already established a prostate cancer support foundation called Prostate Cancer Support Heritage (ProCaSH) that seeks to provide improving support for patients and those significant them. I seek to advocate and through a collaborative effort, ensure that the government and relevant stakeholders prioritise the health and social needs of patients who require palliative services.*

### ***How is being a member of IPCFRC relevant to your work?***

*The IPCFRC provides a platform to share rich experience on best practices about family caregiving research, practices and education. It serves as a pool of potential collaborators in research involving family caregiving.*

Yakubu's specific area of interest in family caregiver research is: 'Home-based care for advanced prostate cancer patients by family caregivers'. If you would like to know more about Yakubu and his work, you can contact him directly at [Yakubu.Salifu@nottingham.ac.uk](mailto:Yakubu.Salifu@nottingham.ac.uk) or [salid32@yahoo.com](mailto:salid32@yahoo.com)

## Would you like to be profiled in the IPCFRC e-News?

One of the key objectives of the IPCFRC is to encourage researchers interested in family caregiver research to make connections and collaborate. To help enable this we would like to offer members the opportunity to be profiled in the IPCFRC e-News. One researcher will be profiled within each edition.

If you are interested in being considered, please provide the details below to [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC member profile'.

Please provide the following details: Your Name, Professional Role/Title, Discipline, Institution, City/Country, Specific area of interest in family caregiver research and your Email address (so that other members can contact you directly).

## Review of literature related to family carer research

One of the initiatives of the IPCFRC is to compile a listing of publications related to family caregiver research in palliative care. This list is updated annually, and serves as a key resource to aid those who are looking for peer-reviewed publications related to family caregivers. The 2017 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

## Upcoming IPCFRC Event

An open meeting for current and prospective IPCFRC members at the [10th World Research Congress of the European Association for Palliative Care (EAPC)] in Bern, Switzerland in May 2018 is currently under planning. We will update you once the details are confirmed.

Open meetings provide the opportunity for members and prospective members to hear about what is happening in the IPCFRC community and what IPCFRC has to offer, as well as meet the IPCFRC Executive Committee and their fellow IPCFRC members.

## Conferences relevant to IPCFRC members

2<sup>nd</sup> National Symposium for Academic Palliative Care Education & Research

Dates: September 28-29, 2017

Location: San Diego CA, USA

Website: [2<sup>nd</sup> National Symposium for Academic Palliative Care Education & Research]

7<sup>th</sup> International Carers Conference

Dates: October 4-6, 2017

Location: Adelaide SA, Australia

Website: [7<sup>th</sup> International Carers Conference]

2017 Marie Curie Annual Palliative Care Research Conference

Date: October 6, 2017

Location: London, UK

Website: [2017 Marie Curie Annual Palliative Care Research Conference]

44<sup>th</sup> Clinical Oncology Society of Australia Annual Scientific Meeting

Dates: November 13-15, 2017

Location: Sydney, Australia

Website: [COSA ASM 2017]

10<sup>th</sup> World Research Congress of the European Association for Palliative Care (EAPC)

Dates: May 24-26, 2018

Location: Bern, Switzerland

Website: [EAPC 2018]

21<sup>st</sup> Cancer Nurses Society of Australia (CNSA) Annual Congress

Dates: June 21-23, 2018

Location: Brisbane, Australia

Abstract submissions open on 1 November 2017

Website: [CNSA 2018]

5<sup>th</sup> Australian Palliative Care Research Colloquium

Dates: October 26-27, 2017

Location: Melbourne VIC, Australia

Abstract submissions open until 20 September 2017

Website: [5APCRC]

## Membership

The IPCFRC has 233 registered members from many countries of the world, including; Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK & USA.

Individuals from all continents with a genuine interest in palliative care research related to family carers may become individual members of the IPCFRC. Membership is free. To formalise your membership please complete the [online form] on the IPCFRC website.

## Recent articles relevant to IPCFRC members

In each edition we will feature some recently published articles relevant to IPCFRC members.

If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC community, please email [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

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Aoun SM, Deas K, Kristjanson LJ, Kissane DW. (2017). Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care*. 15(1):32-43.

Aoun S, Slatyer S, Deas K, Nekolaichuk C. (2017). Family Caregiver Participation in Palliative Care Research: Challenging the Myth. *J Pain Symptom Manage*. 53(5):851-861.

Aoun SM, Breen LJ, Oliver D, Henderson RD, Edis R, O'Connor M, Howting D, Harris R, Birks C. (2017). Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey. *J Neurol Sci*. 372:144-151.

Coelho A, Barbosa A. (2017). Family Anticipatory Grief: An Integrative Literature Review. *Am J Hosp Palliat Care*. 34(8):774-785.

Davies N, Rait G, Maio L, Iliffe S. (2017). Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study. *Palliat Med*. 31(8):726-733.

Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. (2017). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ Support Palliat Care*. 7(3):326-334.

Hansen L, Rosenkranz SJ, Wherity K, Sasaki A. (2017). Living With Hepatocellular Carcinoma Near the End of Life: Family Caregivers' Perspectives. *Oncol Nurs Forum*. 44(5):562-570.

Hudson P, Hall C, Boughey A, Roulston A. (2017). Bereavement support standards and bereavement care pathway for quality palliative care provision. *Palliat Support Care*. doi: 10.1017/S1478951517000451. [Epub ahead of print].

Ryan T, Amen KM, McKeown J. (2017). The advance care planning experiences of people with dementia, family caregivers and professionals: a synthesis of the qualitative literature. *Ann Palliat Med*. 6(4):380-389.

### Forward IPCFRC to a friend!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for [\[free membership\]](#)!

### Update your details!

We are now collecting information on member research interests and expertise. [\[Update your details now\]](#)

### Unsubscribe

If you are no longer interested in receiving correspondence from us, please unsubscribe by emailing: [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au)