

HFA Nurse Training Fellowship

Final report

Fellow	M.E. (Ineke) Lokker RN, MSc
Fellowship period	August 2012 – February 2013
Research project	The impact of Heart Failure symptoms in South Africa: a prospective observational study in patients with NYHA Grade III/IV heart failure
Institution	Department of Palliative Medicine, University of Cape Town
Supervisors	University of Cape Town: Liz Gwyther, Richard Harding Erasmus Medical Centre: Agnes van der Heide, Lia van Zuylen Heart Failure Association: Jillian Riley

The Heart Failure Impact Study

Period preceding fellowship

After being awarded the Nurse Training Fellowship I started working on the preparations for the study: attaining ethical approval from the University and approval to perform research at Groote Schuur hospital, arranging translation of research documents (information sheet, consent form, questionnaires), drafting of a SOP (standard operating procedure), meeting with the department heads of Cardiology (Professor Commerford), Emergency medicine (dr. Crede) and General Medicine (dr Raubenheimer). As part of these preparations I travelled to Cape Town, for one week, in May 2012.

Fellowship period

My fellowship at the University of Cape Town officially started July 25 when I arrived in Cape Town. Before we could start data-collection at Groote Schuur hospital, a number of issues needed to be done. South Africa is a linguistically heterogeneous country. Within the Cape Town-region three languages are most prominent; English, Afrikaans and Xhosa. To be able to interview patients in their first language, a research assistant fluent in these three languages was necessary. Unfortunately the research assistant that was intended to assist during the study withdrew himself just before the start of the study. The largest part of August was therefore used for finding and training a new assistant. I am very grateful to the HPCA (Hospice Palliative Care Association of South Africa) for funding this assistant. The study consisted of three separate measurements at time points 0, 3 months and 6 months. Patient inclusion and data collection at Groote Schuur hospital for measurement one started on August 28 and continued until November. During this period, every Monday till Friday, the emergency unit, emergency admission unit, cardiology outpatient clinic, cardiology ward, cardiology ICU en four general medicine wards at Groote Schuur hospital were visited multiple times a day, by myself and the research assistant, to look for eligible patients. Doctors at these departments were asked whether they had admitted (or seen at the outpatient clinic) any patients aged 18 years of older, able to give informed consent, diagnosed with stage III/IV NYHA Heart Failure and able to communicate in English, Afrikaans or Xhosa. A total of 233 patients met the inclusion criteria of which 230 patients consented to participate in this study and completed measurement one during a face-to-face interview. All data were first collected on a paper copy of the questionnaire and afterwards entered into a digital data collection tool, which was developed specifically for this study. Measurements two and three were performed telephonically with an interval of approximately ten weeks. A total of 221 patients completed measurement two. Every measurement took approximately 30 minutes to be completed.

Period following fellowship

After I returned to The Netherlands data collection for measurement three continued by the research assistant in South Africa until the end of march. A total of 221 patients completed measurement three. During the study seven patients died and two patients were lost to follow-up. Current and scheduled activities include checking the database of measurements two and three for missing values, preparing four poster presentations for two international congresses (see below) and drafting several articles.

Scientific output

Abstracts

Two poster presentations during the Heart Failure Congress 2013

- Lokker M.E., Gwyther L., Magona P., Riley J., van Zuylen L., van der Heide A., Harding R.
The prevalence and burden of physical and psychological symptoms in patients with advanced Heart Failure attending a South African public hospital.
- Lokker M.E., Gwyther L., Magona P., Riley J., van Zuylen L., van der Heide A., Harding R.
Depressive symptoms in patients with advanced heart failure attending a South African public hospital.

Two poster presentations during the 13th World congress of the European Association for Palliative Care

- Lokker ME, Harding R, Gwyther L, Cummerford P, Riley J, Magona P, Van Zuylen L, Van der Heide A.
The prevalence and burden of physical and psychological symptoms in patients with Heart Failure attending a South African public hospital.
- Harding R, Lokker M.E., Gwyther L, Cummerford P, Riley J, Van Zuylen C, Van der Heide A.
Palliative Care Related Problems among patients with Heart Failure attending a public hospital in South Africa.

Articles

Several articles will be drafted from this study based on the cross sectional data (measurement one) as well as the longitudinal data (all measurements).

Reflections

Living in another country

For the duration of the study I moved to Cape Town to live there. Living in another country was enriching to me. I got the opportunity to see the country as an inhabitant instead of a tourist. South Africa is a country with a distinct history. And it will probably take several generations to overcome the effects of the apartheid-regime. However, a lot of people whom I have met showed a remarkable resilience from that history. South Africans are very social people, 'outside', 'together' and 'join' are words often used. During my stay I became a part of the research group involved in palliative medicine studies. Both my colleagues and the friends I made during my stay made me feel very welcome in their midst. Being in another country also means adapting to social norms typical for a country. Social interaction and small talk proved to be very important when you want to get something done. Sweets and chocolates were also very important. I learned quickly that the healthcare staff was very willing to participate after a gift of chocolates. So these gifts were repeated a few times during patient inclusion.

Research collaborations

During this study several collaborations needed to be established. The first collaboration was the formation of the project steering group as listed on the front of this document. The project group met regularly (every 4-6 weeks) via skype/ teleconference. I have regarded these meetings as very helpful and very stimulating for my work. A second important collaboration was with the healthcare workers in the hospital. Thanks to already existing collaborations between the head of the palliative medicine department (Liz Gwyther) and several department heads in the hospital we could set up appointments with these department heads. Both Liz Gwyther as well as Richard Harding have helped a lot in ascertaining the approval from the department heads. All department heads have been very helpful in introducing us and the study to the responsible nurses and doctors per unit or ward. After the introduction it was important that we were present at the wards and units on a regular basis. This meant several visits to wards each day and being present for the duration of a clinic (whole afternoon or morning) at the outpatient clinic.

Transferring knowledge

During my stay in Cape Town I have been interviewed for Monitor (see appendix), the Dutch journal of the Erasmus Medical Centre targeted at external contacts (politicians, policymakers, journalists) . After this original publication, the article was republished by Cordiaal, the Dutch journal of the Dutch society for cardiovascular nurses. I have presented the preliminary results of the cross-sectional data (measurement 1) at the department of Cardiology in Cape Town, to the Ethical committee of Erasmus Medical Centre and to my the Dutch research group which is involved in care and decision making at the end of life. Currently I am working on the first scientific article out of the study which will be based on the cross-sectional data. Besides a primary focus on scientific publications I also want to share this knowledge through non-scientific channels and I am happy that I have already been asked by Cordiaal for articles about the study and its results.

Extremely valuable

I am very happy that I got the opportunity to travel to Cape Town to perform this study. I thank the HFA for providing this fellowship and awarding me with it. A good (nurse)researcher is able to look beyond the scope of what is right in front of her/him. Being able, thanks to this fellowship, to travel abroad for a research project enabled me to widen my scope.