

2008 Mid-term Report ACADEMIC EXCHANGE PROGRAMME

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Title

Impact and Treatment of Lymphedema Following Breast Cancer Treatment –
Phase 2 Educational Training and Research Including Cancer Registry Building

Building on TICIPS Principles and Collaborations

This completed Phase 2 faculty exchange partnership successfully built on the already considerable successes of the NIH CAM-funded TICIPS UM/UWC program headed by Dr. Quinton Johnson (UWC) and Dr. William Folk (MU) and the preliminary successes of Phase 1 of the 2007 UMSAEP exchange. Quoting from the TICIPS summary, we have further developed the project built on the principles set by TICIPS by using a partnership with the traditional healers and other health care providers (including lymphedema (LE) therapists, herbalists, physicians, nurses, physiotherapists, occupational therapists, homeopathic healers, and others as identified), patients, and family/lay care-givers based on mutual respect. Based on the newly identified gap in the health infrastructure in South Africa (RSA) in which we learned during phase 1 that no cancer registry has been in existence over the last 17 years (a data base essential to provide a baseline for measurement of outcomes and improvements in health care), we have also taken the initial step in creating a partnership in building a foundation for the establishment of a cancer registry for the Western Cape, initially, and, subsequently, the whole of RSA.

In the completed Phase 2, research and education/training conducted during the 2008 faculty exchange continued to build upon the trust-building foundation of the TICIPS program. We worked with the Traditional Healer core, other TICIPS investigators, and other native RSA healers to meet and include in planning key people who will share from their expert understanding of RSA customs and traditions in assessing and managing LE. Working collaboratively, as equal partners, with the traditional healers, the practicing nurses and therapists, students, and patients, facilitated the continued development of a program of clinical education and research that will holistically incorporate the best attributes of traditional, indigenous, homeopathic, and allopathic healing approaches. Additionally, we have worked with partners in the UWC, MU, provincial and national cancer societies to lay the foundation for a national cancer and LE registry essential to the evaluation of health outcomes, including our targeted programs in breast cancer LE.

The first overall aim of the collaboration was the continuance of the reciprocal relationship of exchanging expertise and enhancing skill training and education on the best ways to manage LE, while evaluating and integrating specialized massage therapy, traditional, indigenous and homeopathic approaches to LE self care, concentrating on women living in rural/ poor/ neglected areas.

The second overall aim was the collaboration with the governmental and nongovernmental institutions in RSA, UWC, and MU SONs for the establishment of cancer and lymphedema registries as a baseline for further evaluation of program outcomes and progress in the greater effort toward early detection and treatment of cancers such as breast cancer and the detection and treatment of cancer survival outcomes such as lymphedema.

Objective of visits.

Prof. Armer visited UWC in June and July of 2008 for four weeks. She joined with partners at UWC including faculty of Schools of Nursing and Public Health and TICIPS investigators. The objective of this visit was the continuing review of the theses of masters nursing students that are participating in the research project. She is assisting in the supervision of the development of the dissertation proposal for the doctoral student. She also successfully guided the

development and offering of a first-ever RSA 135-hour intensive course in assessment and manual methods of treating LE with collaboration of Prof. Nikodem, a trained practicing LE therapist from the MU Ellis Fischel Cancer Center (Vickie Parker, OT, CLT-LANA), and an expert instructor of LE therapy from NIH Bethesda Naval Hospital (Nicole Stout, PT, CLT-LANA). The course included 17 participants (health professionals including occupational and physical therapists, registered nurses, and massage therapists) from RSA, 2 graduate nursing students from Ghana studying in RSA, 1 graduate nursing student from Argentina studying in RSA, and 1 graduate nursing student from America travelling with Prof. Armer. All students were very eager and committed to further their knowledge of LE treatment, and will continue to work closely with Profs. Nikodem and Armer towards the goal of establishing a network of LE therapists in RSA and instituting cancer and LE registries, as well as multiple other goals that will serve to enhance health care in RSA. An addition to the exchange was the assessment of this first-ever LE therapy class, performed by one graduate student and one undergraduate student. An evaluation tool was developed and field notes were taken in order to assess the 2008 course for possible barriers to learning the material, which is of both a theoretical and a practical nature, with the goal of improving the future courses.

Prof. Armer participated in planning for the fore-mentioned design of the cancer and LE registries with Prof. Nikodem, Ms. Marco (CANSAs employee and PhD student), and the Ministry of Health. Prof. Armer also assisted in the planning and piloting of a self-care intervention education program for women at risk for and suffering from LE in the community. In addition she gave guest lectures, interviewed patients, traditional healers, and therapists, and visited facilities that offered LE management to clients (Pretoria, Bloemfontein, Cape Town, and East London).

Prof. Nikodem travelled to Winnipeg, Canada, for the World Breast Cancer Congress in June 2008, and met with Prof. Armer and members of her team expert in database management, Dr. Chi-Ren Shyu and Dr. Wannapa Mahamaneerat from the MU Health Informatics Institute, and other appropriate parties for the planning of the establishment of the South Africa Cancer Registry. The planning meeting took place around the conference, the venue at which preliminary data from the July 2007 exchange was presented. The objective of this MU/North American visit was to consult and lay the foundation to establish the national cancer registry with a pilot in the Western Cape province. Upon her return, Prof. Nikodem shared the knowledge with UWC faculty and students, CANSAs, the Ministry of Health, and other health care providers who will partner in the development of the cancer registry.

Intended project outcomes and evaluation: The outcomes of the objectives were measurable and achieved or in progress:

1. Output of three mini theses (three UWC masters students: a, b, c) and one doctoral dissertation (d, e) and publications in peer reviewed journals – in progress and complete.
 - a) Systematic review on management of LE (proposal completed).
 - b) The use of traditional, indigenous and homeopathic approaches in rural RSA to treat limb swelling of LE (managing, reducing swelling, treating infection). This will be done by eliciting ways that traditional healers treat limb swelling of LE through interviews and observations (IRB MU consent obtained-ready to be forwarded for UWC ethics permission; three interviews with traditional healers completed in 2007, 1 in 2008)
 - c) Piloting a self-care intervention aimed at reducing the occurrence of LE in women (pilot nearing completion with mid-project evaluation complete and intervention modification planned).
 - d) Development of a 20-credit module (135-clock hours didactic and practical) curriculum in LE management through UWC for health professionals of all disciplines implemented in July 2008- one year earlier than originally planned (21 students from South Africa, Argentina, United States and Ghana completed the course, with planning underway for two such courses in 2009).

- e) Planning continues for the establishment of cancer and LE registries in the Western Cape as a pilot for the whole of South Africa to be launched in 2009.
- f) Ongoing collaboration with UWC and MU faculty as well as local, national, and international LE therapists and traditional healers in planning possible educational programs that may develop after the findings of the above four outcomes (a, b, c, d) (educational presentations and collaborations completed in Western Cape and East London; multidisciplinary meetings in Pretoria, Western Cape, and Bloemfontein carried out).
- g) Ongoing collaboration with UWC and MU faculty as well as local, national, and international healthy entities in planning possible educational, research, and training programs that may develop after the activities of the above outcome in cancer and lymphedema registry development (e) (2008 collaborations have exceeded the 2008 goals and laid a strong foundation for 2009 and 2010 objectives).

Project design and methodology:

Activities took place in both South Africa and North America with nursing/public health/biomedical departments from both UWC and MU traveling to the collaborator's home continent for training and teaching. The master students (mini theses) and doctoral student (dissertation) are being co-supervised by the two exchange faculty.

The **first objective** was the completion of a literature review in the form of a systematic review on management of LE. All the principles of a Cochrane Systematic review will be followed in collaboration with the South African Cochrane Centre. The masters thesis proposal, which will focus on this outcome has been written and approved.

The **second objective** involved the completion of a qualitative research process where the use of traditional, indigenous and homeopathic approaches to treat limb swelling of lymphedema will continue to be investigated through interviews and observations with traditional healers and LE therapists. Publications and presentations from these findings are planned; one abstract is under review for the February 2009 Oncology Nursing Society Research Congress.

The **third objective** was to apply the findings of a pilot intervention study completed at MU in which the intervention will be reviewed and adapted as indicated for application in South Africa as an intervention education self care program to reduce the occurrence of LE in women who are at registry risk of LE after breast cancer. This MU project is nearing completion and modifications to the intervention protocol have been made. Interim findings have been shared at an international nursing congress and with therapists in South Africa. Final outcomes will be shared when available and plans for implementation of a modified protocol in South Africa will be completed.

The **fourth objective** involved the planning, development, and preparation for implementation of the 20-credit modules (135 clock hours) for formal instruction in lymphedema management based on international standards as recognized by the certification board of the Lymphology Association of North America (LANA). This initial South Africa course was presented between June 30-July 12, 2008, one year earlier than originally projected. The successful first course welcomed 21 students, health professionals from South Africa, Ghana, Argentina, and America. Two courses are planned for 2009, one at UWC and one at Pretoria Tshwane University of Technology.

The **fifth objective** involved the consultation and foundation-building for the data base to comprise the cancer and lymphedema registries to be piloted in the Western Cape and applied to the whole of South Africa. This goal will continue into 2009 as the planning and implementation of the lymphedema management course became the 2008 priority due to the urgency of the need and the readiness of the health professionals for specialized training in lymphedema.

Time line:

Feb-May 2008: intensive email correspondence took place to supervise protocols for one mini

thesis project (proposal completed), one dissertation proposal, and two pending masters proposals, with care to ensure that all four projects go through both MU and UWC ethical boards and Senates.

Feb-May 2008: Analysis of literature and writing of systematic review (email correspondence and supervision of student). Prof. Nikodem directly taught the three masters students and doctoral student who are involved with the project, and Prof. Armer is co-supervising these students and projects. Collaboration with TICIPS group and lymphedema therapists to identify possible sites/traditional healers for further qualitative interviews will be identified as necessary. The masters student participated in the 135-hour course and was trained in interviews as well.

June 2008: Prof. Nikodem traveled to Winnipeg to participate in the World Breast Cancer Congress. She and Prof. Armer met with MU Health Informatics experts to begin to plan and design the foundation of the cancer and lymphedema registries to be applied in Western Cape and the whole of South Africa. Dr. Nikodem co-presented the case study from the 2008 breast cancer survivorship study in South Africa.

Jan-Dec 2008: Ongoing co-supervision on three masters mini theses till completion of projects.

July 2008: Prof. Armer traveled to UWC to participate in proposal development by the doctoral student and review of the masters students' mini-theses. Prof. Nikodem and Prof. Armer met with TICIPS collaborators, CANSA, and Health Ministry collaborators, and therapists and patients. During this time the collaborators will work on the proposals for the 3 objectives as stated above [systematic review (proposal completed), qualitative data collection (in progress), pilot of self care intervention (Missouri pilot continues in progress)]. IRB approval to extend the Missouri work to South Africa has been approved and ethics review is in progress at UWC for the next step of the research. Prof. Armer accompanied students and trained field workers in conducting interviews with traditional healers and patients on the management of LE after breast surgery. Prof. Armer coordinated the planning for the 135-hour course of instruction in LE measurement and management and assisted in setting up the pilot study for the self care intervention. Prof. Armer guest lectured to and met with LE therapists and clients in the Western Cape, Pretoria, East London, and Bloemfontein on LE research findings and educational best clinical practices in LE management and risk reduction, cancer survivorship and LE self care. Prof. Armer also guest lectured at UWC and community venues. A videotape for cancer patients and families sponsored by UWC and CANSA will be edited and produced from case studies presented to the LE course. Press releases about the inaugural course are being developed by UWC and MU and will showcase the collaborative efforts between the two universities.

Proposed budget, including matching funding (use attached budget form):

Amount requested and awarded: R **\$10,000 UMSAEP**
Matching: R \$7,500 alternative funding

**Funds were received from various other sponsors such as MUSSON, Verna and Jim Adwell Rhodes International Travel Fund and MU graduate travel funds (MU SON and informatics graduate students support to World Breast Cancer Congress), Scholarships (waiver of fees) for the UWC doctoral student's and MU graduate student's course fees for the lymphedema course offered at UWC, and UWC senate research grant for 2008.

Prof Nikodem received registration support for international travelers attending the World Breast Cancer Congress.