

## 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 educationy-1(a)7D/cP8.(ub)lTd ( p.ym)-2(l[(e)r1(a)-1(t T\* [(unde)-

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

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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.

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