EONS Research Travel Grant

Learning Report

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CNS - Radiation-Oncology Outpatient Clinic at CHUV

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London and Belfast

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1. Overview of the EONS Research Travel Grant

The EONS Research Travel Grant (RTG) was a unique and enriching moment of learning, sharing and improvement on my cancer nursing career. It took place between the 14th and the 28th of April 2018. From the 14th to the 21st of April I had the chance to learn in some of the best hospitals and clinics of London in the cancer domain. I travelled to Belfast the 21st of April and visited the three main cancer centers, before coming back to Switzerland on the 28th of April. This RTG was enabled by two main promoters: Professor Mary Wells and Doctor (and CNS) Cherith Semple. They were highly enthusiastic and spared no energies on planning and executing the program according to my objectives.

In London, I went to:

- The Imperial College Healthcare NHS Trust
    - Charing Cross Hospital
      Imperial College – MSc in Health Policy
- The Royal Marsden NHS Foundation Trust
- The London Clinic

In Belfast I visited:

- The Northern Ireland Cancer Centre (Belfast City Hospital)
- The Royal Victoria Hospital
- The Ulster Hospital (South Eastern Health and Social Care Trust)
- The Ulster University (Jordanstown campus)
- The first Northern Ireland CNS meeting

The initial plan was to do part of the observership at Stirling University with Professor Mary Wells. When we discussed this the first time, she was about to move to London to start a new professional challenge and we planned the details of my trip so that I could profit the most from the observership.

2. Objectives

The learning objectives were related to my current nursing activity as a CNS working in a radiation-oncology outpatient clinic and as a project manager for a new nursing consultation. In February 2018 we started a nursing consultation with the head and neck (H&N) patients undergoing radiotherapy treatments. Besides standard care, the patients have 3 nursing consultations during the treatment period: right before starting the treatment; between the 3rd and 4th weeks of treatment; between the 5th and 6th weeks of treatment. These patients are screened for malnutrition, pain, smoking and alcohol consumption, oral care habits and trismus; they receive education on self-care in the domains of skin and mouth care, nutrition and pain medication management; they are referred to other healthcare professionals accordingly to screening results. A weekly doctor-dietitian-nurse meeting was set up. This intervention incorporates a research component as it evaluates the consultation feasibility and the patient outcomes. A control group of at least 75 patients with standard care will be evaluated against an intervention group of 75 other patients after the start of the nursing consultation. Measurement tools for the evaluation will include symptoms using the MD Anderson Symptom Inventory for Head and Neck patients, patient satisfaction and self-efficacy using a paper questionnaire and clinical data such as weight loss, mucositis grade and mouth/neck pain intensity.

Besides the extensive literature research and the discussion with most of the healthcare professionals that take part in H&N patients' treatment, I've realized that there were three main topics that needed further research: the implementation of advanced practice roles (specifically CNS roles in radiation oncology units), the use of assessment tools and patient reported outcomes to guide nursing interventions (and to increase collaboration) and the CNS role on the provision of follow-up care and survivorship issues. The following objectives were defined:

In London:

- To identify the nursing sensitive outcomes of nurse-led clinics for H&N patients undergoing radiotherapy

- To discuss patient reported outcomes and assessment tools suitable for radiotherapy settings

- To better understand how to plan the development, introduction and long-term implementation of nurse-led clinics/nurse-led care in radiation oncology

- To understand the CNS roles evolution in the NHS

- To observe the CNS/RN work at Imperial College, also to understand the different roles of RN's, CNS's, other specialized nurses and NP's in an H&N clinic (focus on teamwork and communication)

In Belfast:

- To clarify the clinical nurse specialist roles, implementation process and care planning in an H&N clinic (facilitators and barriers to role implementation and strategies used by the CNS and nursing team)

- To understand the different roles of RN's, other specialized nurses and NP's in an H&N clinic (as well as teamwork and communication)

- To identify the advantages and disadvantages of the use of a global screening and assessment tools in a nurse consultation context (reported by the nurses and patients themselves) and to discuss the tool's development and implementation processes.

- To clarify the CNS role on the provision of follow-up care and survivorship issues (care planning, organization, etc.)

- To identify the outcomes measured and their implication to patient care/clinic financing-budget.

3. Learning experiences

I met Mary Wells on the first day of my observership. She occupies the post of Lead Nurse for Research within the Imperial College Trust and she is responsible for developing clinical academic nursing, professional leadership for research nurses and determining the nursing research priorities and planning their implementation throughout the Trust. We discussed the CNS role in cancer care in the UK and in Switzerland. CNS's development started in the early 1970's in the UK, as in Switzerland it only started in the beginning of 2000's. Most of CNS oncology posts started with the aid of the Macmillan Cancer Support: this charity sponsors CNS roles during the first 3 years and the hospital is required to keep the job post open afterwards. In Switzerland CNS's have been hired at different moments, places and rhythms and their coverage it's still very low.

We discussed the document "A competence framework for nurses – caring for patients with and beyond cancer" (Macmillan, 2014) and the work that's being done to define oncology nurses' education and competences across all the cancer spectrums in the UK. Usually, CNS's in oncology have a post-graduate formation on oncology nursing that can last up to 2 years, ANP's (advanced nurse practitioners) have a master's degree that combines pharmacology, prescription of medication and exams and there are prescription courses for allied healthcare professionals (1 year or more). In Switzerland the first NP's will start their formation in autumn 2018. This gap between both countries, in terms of advanced practice nursing formation, could explain other differences that will be mentioned in this report. Improving formation requirements for oncology nurses and creating financial packs (through charities, foundations, etc.) to help the introduction of CNS roles in practice could be helpful, but cultural barriers must be surpassed.

In terms of research, we've discussed the H&N nursing consultation project and Mary Wells made some improvement recommendations regarding the evaluation phase, which will be presented in the chapter "Findings".

During the observership, I was able to witness different CNS roles, competencies and care models. Because the description of each site would be too exhaustive, a table presenting the differences and similarities is presented below.

	Nursing care available	**Pre-treatment**	**On treatment**	**Follow-up**	**Assessment tools**	**Others**
Charing Cross	-CNS exclusively for H&N patients undergoing **radiotherapy** / -Nursing standard care on site (1 nurse)	-CNS presence on multidisciplinary team (MDT) reviews -Announce-ment consultation – shared with the doctor -Pre-treatment clinic – shared	-Weekly on-treatment clinic CNS with SALT and Dietitian -Information exchange with doctor as needed	-No CNS follow-up -One afternoon for health and wellbeing event	-Holistic Needs Assessment (HNA) on beginning and middle of treatment by CNS. - VHNSS (Vanderbilt Head and Neck	- 4 linear accelerators (LINACS) -Estimate 100 new H&N patients per year -No clerk support

		with Speech and Language Therapist (SALT) and Dietitian			Symptom Survey) by doctor - Same records template for CNS, SALT and dietitian + duplication for CNS on another system	
Royal Marsden	-2 CNS's exclusively for H&N patients undergoing **radiotherapy** / -Nursing standard care on site (one nurse)	-Pre-treatment clinic – shared with Speech and Language Therapist (SALT) and Dietitian	-Weekly on-treatment clinic CNS with SALT and Dietitian	-Separated follow-up with SALT and dietitian (CNS on call if needed) -CNS consulta-tions once a week until opiates withdrawal (guidelines) - Weekly meetings week 1,2,3,4,6,8 and 13	-Distress thermome-ter on pre-treatment -MD Anderson Dysphagia Inventory (MDADI), Performan-ce status scale for head and neck cancer (PSS/HN), Perceptual voice evaluation (GRBAS) and Maximum interincisor opening, all by SALT	-4 LINACS, 1 cyberknife -CNS has formation in oncology and clinical assessment -CNS manages chemothera-py and radiotherapy combined -Nasal fibroscopy observation -NP function except for prescription -Full clerk support
London Clinic	-CNS for H&N patients during the **whole care path** -Nursing standard care on site (1 nurse) except for H&N and breast cancer	-Presence on multidisciplina ry team (MDT) reviews. Pre-treatment clinic if surgery before (evaluates the need for SALT/Dietitian)	-Weekly shared clinic CNS with/without Speech and Language Therapist (SALT) and Dietitian	-According to patient needs (frequently by e-mail - telephone) -Doctor tends to follow-up one month after end of treatment	-London HNA Tool beginning and end -Toxicity evaluation using RTOG	-2 LINACS and 1 Cyberkinfe
Royal Victoria	-CNS for H&N patients	-Presence on multidisciplina	Weekly outpatient	-CNS-ledfollow-	-Electronic HNA – PCI	-Full clerk support

Hospital	managed under the care of theplastic **surgery** & ENToutpatient clinic	ry team (MDT) reviews. Specialized HN Radiographer (RTT)* as well -Pre-treatment clinic with doctor -Pre-optimisation before surgery clinic (with SALT and dietitian)	clinic	up after 2 years if low risk	and UWQoLv 4(volunteer worker presents it to the patient and up to date access to patient scores and 3 main concerns)	-Weekly team meeting -CNS formation on health assessment and PhD
Belfast Hospital – NI Cancer Centre	-CNS exclusively for H&N patients undergoing **radiotherapy** / -Nursing standard care on site (2-4 nurses) + 2 brachytherapy	-Pre-treatment clinic with doctor - CNS and specialized RTT* together 1 week after the doctor - Baseline by SALT	-Weekly on-treatment clinic CNS or doctor (SALT and Dietitian contacted when needed) + RTT on a separate day - CNS doing on treatment follow-up so that doctors can perform other activities	Specialized RTT* Shared care model between CNS /RTT and medical team	-HNA on the beginning, end and 6 months after treatment	-Estimate 130 new H&N patients per year (around 360 new, on treatment and palliative care) - 10 LINACS with 300 to 350 patients treated per day -nursing standard care to 35 to 40 patients per day -CNS had a 2 year post-grad formation on oncology
Ulster Hospital	-CNS for H&N **surgery** patients inpatient and outpatient clinic	-Advancement of patient file/imagery in preparation for MDT -Announce-ment consultation – shared with the doctor	-Participation in ward rounds 2/3 times a week Collaboration with dietitian and SALT according to patient needs	-Follow-up 6 weeks after surgery and 5 to 6 months post-treatments	-Mcmillan information package -HNA 6 weeks after surgery and 5 to 6 months post-treatments	-CNS records separated from dietitians and SALT's. -CNS formation on health assessment module,

		-CNS consultation right after (clarifying doctor information, psychological and social support, employment status)	-Consultation 6 weeks after surgery -CNS coordinates information between RN's and doctors and other keyworkers, manages complex patients			advanced communica-tion skills and PhD

* The specialized RTT has an additional formation on Prescribing for Healthcare Professionals (independent and supplementary prescribers – 1 year) and 1 year of advanced practice. She's responsible for the patient pathway related to radiotherapy schedules/checkpoints, peer-review of radiotherapy plans with doctors and managing toxicities during the follow-up phase.

** Patients with other pathologies, in London and Belfast: CNS with a more transversal role, pathway coordinator. Only H&N patients have dedicated CNS roles, for both surgery and radiotherapy.

One of the highlights of the RTG was the attendance on the MSc in Health Policy at Imperial college and a part of the course "Health Care Delivery: translating policy into practice". The students presented policy propositions according to several theoretical frameworks and those were discussed with the rest of the class. Afterwards, Professor Sir Harry Burns (former Chief Medical Officer of Scotland) gave a speech on social determinants of health, which highlighted the social disparities and health status of different groups within Scottish population. Both moments reminded me that nurses occupy positions within the healthcare system and within social groups that allows them to detect healthcare needs and to develop the strategies to address those needs. But they also need the knowledge and the right partnerships in order to write and support the implementation of healthcare policy. In the future, nurses will be even more influential in care delivery. They must have a seat at the policy table or they will be subjected to whatever policy may be created without their input.

Another great learning moment of this RTG was the 1st CNS conference of Northern Ireland that took place on 25 April 2018. The presentations focused of CNS roles, model experiences (in oncology and other health care domains) and the presentation of the new CNS Key Performance Indicators (KPI) framework. Cancer survival and survivorship issues were major topics of discussion. CNS's are more and more requested to care for this specific population and to answer to their needs: we witness an augmentation of the number of complex care pathways, of the patients with co-morbidities, of the understanding of late effects on cancer survivors and of the number of patients with advanced incurable disease. According to the speakers, access to CNS care could improve patient experience, enhance coordination and improve the use of existing resources. Doctors alone cannot withstand the burden of care to this particular population.

In order to render healthcare systems sustainable, efforts are being made to stratify patients according to risk of recurrence, to educate them on supported self-care and surveillance and to change the focus from routine follow-up assessments (expensive and not that effective) to

assess the patients when they have symptoms. Risk stratification models are being tested: patients with moderate to high risk continue to have shared care (patients continue to have face to face, phone or email contact with professionals as part of their follow-up) as patients with lower risk are proposed a self-directed aftercare pathway (patients are educated to self-manage including symptom surveillance, quick access when needed and information on exams required during follow-up period). Common goals within the healthcare teams and established follow-up protocols are fundamental for success: CNS's are capable of conducting the follow-up of low-risk patients.

Research is being made on PRO's (patient reported outcomes), thanks to mandatory HNA as part of the patient evaluation (without a continuous flow of data it's not possible to generate evidence on patient needs, concerns and quality of life). An important point was discussed, as CNS's in general continue to occupy 20% to 30% of their time on clerical work and not on their major roles: as such, providing administrative support becomes vital to increase CNS productivity.

The role of physical exercise as a means of reducing the risk of recurrence, as well as recovery and quality of life was highlighted as essential. Macmillan Move More imitative offers provide physical activity rehabilitation classes, to include modalities like pilates, yoga, mindfulness, golf, walk groups, nordic walking and swimming. This is available for all patients, in all disease stages; adapted activities are proposed according to present status; coaches are trained to detect health complications and contact GPs.

The draft version of KPI for CNS's in Northern Ireland was presented: Service Improvement (such as evidence of how CNS's have played a key role in ongoing service improvements: creation of guidelines); Service Delivery (number of nurse-led clinic appointments; % of MDT meetings CNS in attendance); Holistic Approach (number of patients who are offered and completes a HNA); Patient Information and Support (% of patients who received the right information at the right time from their CNS) and Supportive Professional Activities (evidence of attendance of courses, provision of teaching sessions for other staff, involvement in service audits, policy and protocol development, implementation of national guidelines). These indicators are of extreme importance as they make CNS activity visible, they allow the evaluation of access to nursing care and they serve as benchmarking/quality indicators between institutions.

The last Thursday I went to Ulster University to discuss the research projects that are currently being undertaken within the Cancer Care Research Group (CCRG). I had the chance to listen to the PhD students present their work and an outline of Cherith's current and future research projects. The CCRG projects at Ulster University include:

- Web-based tailored intervention for self-management of reduced shoulder mobility for post-surgery breast cancer patients
- Maximizing sexual wellbeing after prostate cancer: developing and testing support resources
- Supporting families at the end of life
- Physical/psychological needs of patients with multiple dental extraction
- Improving quality of life through the routine use of the patient concerns inventory for head and neck cancer patients: a cluster preference randomized controlled trial
- Sexuality in head and neck patients
- Impact of health and wellbeing events on QoL of head and neck patients
- Implementing enhancing recovery after surgery
- E-learning module to teach nurses and other HC workers to help parent's with cancer talk with their children

One note for patient reported outcomes: both in London and in Belfast, the HNA conducted by CNS's allowed for the healthcare team to focus on the patient needs (and thus being faster and more helpful), for the patients to express themselves and for solutions to be found on the spot (such as counselling, information provision, demanding exams or referring patient to other providers). HNA is well integrated in all the visited sites and it enables real patient-centered care. Most of the sites have a paper-based version but in the Royal Victoria Hospital the nursing and IT team worked together to have a paperless version of both the HNA as well as a QoL questionnaire – a volunteer has been recruited to explain the patients how it works and patients are cooperative towards this innovation. An electronic HNA allows the professionals to have up to date information on patients concerns even before the patient has entered the consultation bureau, it allows nurses and doctors to be in line with patients' needs and to gather and store data much faster and cheaper.

Nursing care staffing and practices varies from one site to another and each context determines a different organization: nevertheless, skin and mouth care products vary greatly and outcomes are not routinely gathered and analyzed is most of the sites. A framework for CNS care is well embedded in the system and the need for this key player is well recognized. Efforts to measure CNS activity are being developed, as stated earlier with the KPI's.

4. Findings

Implementation of advanced practice roles

As stated before, a framework for CNS care is well embedded in the system and the need for this key player is well recognized. In the sites visited:

- The CNS role in cancer care has been promoted and sustained greatly (not only but also) by the Macmillan Cancer Support charity. The ability to fund CNS posts for at least 3 years and their political influence has helped to consolidate this role within cancer care.
- CNS's in radiation oncology are core team members with different competency profiles and activities than staff nurses. Even though some units are starting new CNS consultation modalities the role is well known in cancer care.
- CNS's activities vary, but there's an important amount of direct patient care, guidelines and protocols creation/revision and coaching of the teams.
- Specifically in head and neck cancer, CNS's are responsible for their own separate clinics (pre and on treatment, follow-up) and have the staffing to ensure those clinics.
- It is well recognized that head and neck patients (because their high demand of care) must be evaluated by a CNS on a weekly basis, besides nursing staff and the doctor's evaluation. Most of the clinics are made along with SALT and dietitian which is, in my point of view, beneficial to the patient (needs 1 appointment instead of 3) and the HC professionals (information exchange, teamwork, and follow-up). Other clinics appointments are made with the doctor as well. CNS's are needed to provide holistic and global care to these patients, as stated in the British Association of Head and Neck Oncology Nurses guidelines for head and neck cancer care.
- According to the extension of their formation, some CNS's replace traditional doctor roles and are able to prescribe medication and exams (approaching the role of nurse practitioners which I haven't seen in radiation oncology units) and conducting follow-up clinics alone.
- CNS's roles are very well accepted within HC teams when the planning and implementation of CNS care is done with all HC professionals.
- Senior management support, care protocols/guidelines well defined and the provision of organization and infrastructure (physical location and secretarial support) are determinant for the role success.

Assessment tools and outcomes

- The use of an HNA tool is mandatory and is part of the CNS work. It's an important component of patient centered care and it's well accepted by the patients. It concerns nurses but also doctors and HC professionals.
- Electronic HNA tools can be created within HC institutions and be customized according to the patient needs: they are less expensive, more user-friendly and they allow up to date information and better data storage. On the other hand patients need to be taught at least once on how to use the E-HNA, which demands for an additional person (volunteer, professional) to be present.
- CNS's use other tools to collect data, namely validated scales for symptom screening and assessment (such as RTOG, CTCAE, etc) and they use validated institutional

templates for recording patient evolution and health status. These records are generally not used for research.
- Outcomes are mostly based on the structure (staffing, infrastructure, availability of HNA) and process (number of CNS consultations and wellbeing events conducted). Outcomes based on patient results are not usually collected, analyzed and acted upon.

Survivorship issues

- A great effort is being put upon research and action regarding survivorship issues. Once again charities are one of the drivers for change: among others the Macmillan Cancer Support charity proposes recovery packages (that includes HNA and care planning, treatment summary, cancer care review and health and wellbeing events); Maggie's centres offer architectural spaces that allow patients to share their experiences, to rest and to participate in a variety of activities (yoga, mindfulness, talk groups, etc.)
- CNS's are testing and developing new care models for patients, that includes the use of HNA at key follow-up periods, the monitoring of late effects and relapse, the provision of education on self-surveillance, the referral to other services and the rapid access to specialist advice (using telephone, e-mail, face-to-face meetings). The idea is to make the patient responsible for their own surveillance and to change from fixed follow-up schemes to adapting follow-up according to individual patient needs.
- If properly trained and according to up to date protocols, CNS's global approach may contribute to better care during the survivorship phase (especially if we think about the growing number of patients in the recent years).

Research Project

Several discussions with Mary Wells and Cherith Semple allowed for clarification on the implementation and evaluation of the new nursing consultation. Respecting the cultural background, unit resources and some decisions that had already been taken, the 2 coordinators of this RTG were able to make important recommendations regarding mostly the evaluation phase of the project:

- To perform a cost analysis (analyzing indicators such as nursing personnel time used, avoidable hospital admissions and readmissions, avoidable feeding tube placement, median length of NG feeding);
- Calculating the referrals to other healthcare professionals;
- Regarding sample size (n= 75 patients with standard care with n= 75 patients with the nursing consultation) being careful when comparing subgroups, as well making fewer subgroups (ex: to compare patients with T1+T2 tumor stage with patients with T3+T4 instead of comparing the 4 tumor stage groups separately).
- Regarding demographics, stratify groups according to tumor site (oral cavity, larynx, etc.) and type of radiotherapy (neoadjuvant, adjuvant, single treatment).
- Recruiting master's and PHD researchers to collect and analyze the data could help to reduce the CNS's workload related to this project.
- Invitation (already made by Dr. Simon Rogers) to integrate and evaluate the use of the Patients Concern Inventory as HNA instrument.
- Suggestion for future research project: studying head and neck patients' unmet care needs after 6 months of radiotherapy treatment with standard doctor-led follow-up (in order to understand if there's the need to improve global care and to define CNS care provision during this period).

5. Conclusion and Recommendations

I feel thankful and happy to have had the chance to use this RTG to visit London and Belfast hospitals. It represented a unique and important learning moment and I'd like to thank EONS for making it happen. It is truly an organization that promotes the growth and strengthening of oncology nursing in Europe and around the world. A very special thanks to Prof. Manuela Eicher for motivating me to apply for this RTG, to Prof. Mary Wells and Dr. Cherith Semple for organizing such a complete and rich observership program (and for selecting the best HC Institutions), to my Head Nurse Patricia Debarge, Head of Oncology Nursing Department Pascale Castellani and Vice-Head Nurse Nadia Fucina for welcoming and cooperating to make this RTG possible. I'd also like to thank the CNS Teresa Gascoyne, SALT Grainne Brady, CNS José Barroso, CNS Sandra Jackson, Dr Catherine French, CNS Claire Duffy, CNS Melanie Ardis, Specialist RTT Kar Lee Brown and all the doctors and consultants for their warm welcome, extreme professionalism and for having granted me the opportunity of learning from them.

A few recommendations emerge from this RTG regarding the new nursing consultation project, as well as other aspects of head and neck patients nursing care:

1. Head and Neck patients should have a weekly follow-up provided preferably by specialist nurses (or nurses where it is not possible) besides existing care. This type of care should become available as standard care especially for this type of patients. Currently the nursing consultation model allows for 3 nursing consultations during the treatment period, a number that should be negotiated with nursing management.
2. Nursing consultations should be taken together with other professionals such as SALT and dietitians, at least for a few key-moments and according to their availability.
3. The use of an HNA tool should be mandatory during the beginning and end of radiotherapy treatment, as well as 6 months after treatment. For the time being we are using the MDASI-HN for research purposes but once the research phase is over this should be seriously considered. An electronic version will be proposed to management, as well a way to teach patients to use them.
4. Survivorship should be considered and a doctor-nurse follow-up consultation will be proposed (along with the use of HNA) to management. CNS input at that moment could be beneficial to the patients and their families.
5. CNS-led follow up and stratification of risk will be discussed within the multidisciplinary team.
6. The research recommendations will be evaluated and set in motion as the resources and the context of the unit allows it. Efforts will continue to be made to integrate masters students in our research project (currently there are 2 masters students working on part of the data regarding this project).

Cancer care in the UK is well developed and CNS's are seen as a key-player in HC teams and a key-worker to patients and their families. The role implementation and the impact they have in head and neck cancer patients over more than 30 years is incredible. Swiss radiation oncology units have very good practices available to implement in terms of advanced nursing care. As a CNS working in such a unit, I'll take what I've learned in London and Belfast and I'll work to improve patient care, experience and satisfaction.