Institution: London South Bank University

Unit of Assessment: Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Supportive Care in Children's Cancer Nursing: Improving the management of oral health.

1. Summary of the impact (indicative maximum 100 words)

This research has led to the introduction of widely disseminated and adopted guidelines which have clearly changed practice with regard to assessing risk of oral mucositis and the interventions used. The guidelines have led to improved mouth hygiene, a significant reduction in the use of ineffective interventions, specifically use of Nystatin (estimated to save the NHS a minimum of £463,000 per annum), and the delivery of individualised care to children and young people. These measures have directly led to (i) better mouth care with less discomfort and improved quality of life for the children, (ii) reduced risk of mouth infection, and (iii) reduction in readmissions consequent to mouth infection. This has reduced the cost of treating the acute oral side effects of chemotherapy regimens used in children who have cancer.

2. Underpinning research (indicative maximum 500 words)

The administration of many chemotherapy regimens may be complicated by toxicities that limit clinicians' abilities to deliver the most effective dose of active agents. One such clinically important acute side effect is oral mucositis. Research into this issue, which provides the underpinning research for this Impact case study, was carried out by Faith Gibson (Senior Lecturer) at LSBU during the period 1996 to 2006 (1-6).

In 1996 an Action Research study was undertaken led by Gibson in collaboration with clinical nurses at Great Ormond Street Hospital for Children (GOSH) employing cycles of research to explore oral care practice in a single site. A review of the literature led to the identification of an adult oral assessment instrument to be used to inform clinical decisions. Prior to introducing the instrument into practice, a second problem was diagnosed, relating to the implementation of the current oral care regimen, for which a further literature review was undertaken. The main research output from these initial studies was a mouth care protocol, a flowchart and algorithm, which addressed the needs of children receiving individual modules of chemotherapy. It also resulted in the introduction of an oral assessment instrument for the first time in the UK. The aim of the protocol was to assist nurses and doctors in determining the relative risk of oral mucositis, guiding them to choose the most appropriate intervention. Following active dissemination an evaluation was undertaken, the mouth care protocol was revised and education materials developed. The findings from this study were disseminated through peer-reviewed articles (1), local/national meetings and an international conference.

In response to feedback that the protocol was not always being followed a further cycle of Action Research was undertaken in 2000 (2). This included: structured interviews with health care professionals, vignettes and an analysis of documentary evidence from care plans and prescription charts. This study confirmed areas of concern, notably the indiscriminate use of some oral care products, problems scoring using the oral assessment guide that had been adapted for use in children, and most significantly the failure of an increasing oral score to trigger changes in treatment decisions. As a result a second algorithm was derived that provided clinicians with a treatment regimen corresponding to an increasing and/or decreasing oral assessment score.

Through the above two research studies, the team at GOSH led by Gibson, have developed a pool of knowledge and expertise in the field of oral care treatment of children and are now widely regarded as experts on mouth care in children and young people.

Further research commencing in 2003-4 and funded through a grant from the General Nursing Council (£30,000) investigated the reliability and validity testing of the oral assessment instrument.

This research led to an oral assessment instrument specifically for use with children (4). The instrument developed by Gibson and the team at GOSH is the preferred instrument in the UK (5), and is recommended in the guidelines on mouth care for children treated for cancer (6). The guidelines were developed by the Children's Cancer and Leukaemia Group (CCLG), of which Gibson is a leading member, and the Royal College of Nursing (RCN) using the Scottish Intercollegiate Guidelines Network (SIGN) framework.

3. References to the research (indicative maximum of six references)

1. **Gibson F**, Horsford J and Nelson W. (1997) Oral care-ritualistic practice reconsidered within a framework of action research, *Journal of Cancer Nursing* 1 (4) 183-190. DOI: 10.1016/S1364-9825(97)80517-2
2. Nelson W, **Gibson F**, Hayden S and Morgan N. (2001) Using action research in paediatric oncology to develop an oral care algorithm. *European Journal of Oncology Nursing* 5 (3) 180-189. DOI: 10.1054/ejon.2001.0130
3. Glenny AM, **Gibson F**, Auld L, Clarkson J, Coulson S, Craig J, Eden T, Worthington H. and Pizer B. (2004) A survey of current practice with regard to oral care for children being treated for cancer. *European Journal of Cancer* 40 (8) 1217-24. DOI: 10.1016/j.ejca.2004.01.030
4. **Gibson F**, Cargill J, Allison J, Cole S, Stone J, Begent J and Lucas V. (2006) Establishing content validity of the oral assessment guide in children and young people. *European Journal of Cancer* 42 1817-1825. DOI: 10.1016/j.ejca.2006.02.018
5. **Gibson F**, Auld E, Coulson S, Craig J, Glenny AM. (2010) on behalf of the CCLG/PONF Mouth Care Group. A systematic review of oral assessment instruments: what can we recommend to practitioners in children and young people's cancer care? *Cancer Nursing.* 33, E1-19. DOI: 10.1097/NCC.0b013e3181cb40c0 (also submitted as an output in REF2)
6. Glenny AM, **Gibson F,** Auld E, Coulson S, Clarkson JE, Craig JV, Eden TOB, Khalid T, Worthington HV, Pizer B. (2010) on behalf of the CCLG-PONF Mouth Care Group The Development of Evidence Based Guidelines on Mouth Care for Children, Teenagers and Young Adults Treated for Cancer. *European Journal of Cancer.* 46, 1399-1412. DOI: 10.1016/j.ejca.2010.01.023 (also submitted as an output in REF2)

4. Details of the impact (indicative maximum 750 words)

This case study is an example of the impact of research on Professional Practitioners and Services and specifically the development and implementation of new guidelines for improved, cost effective delivery of mouth care in children with cancer. These first ever mouth care guidelines are still in effect today and continue to be disseminated and communicated widely through the 21 CCLG cancer treatment centres, associated bone marrow transplant units (BMT) and beyond into shared care hospitals, children's hospices and the international cancer community (1-3). The guidelines are included in the BMJ Evidence Centre as part of best practice (4).

An audit of the uptake and use of the guidelines carried out in 2010 (5) by the CCLG revealed that:

(i) the CCLG-PONF guidelines were being used in 19 of the 28 (68%) CCLG centres and associated BMT units;
(ii) consistent advice was given by nurses to patients/parents on basic oral hygiene, and this advice was commensurate with guideline recommendations;
(iii) 90% of centres advised use of fluoride toothpaste (vs 45% prior to the guidelines);
(iv) few therapies outside of the guideline recommendations were being used;
(v) use of Nystatin, the preferred treatment at the time, had reduced by 40% (vs baseline); the guidelines recommended zero usage of Nystatin on the grounds that it was systemically ineffective. This reduction therefore represented a significant step in achieving this zero-use objective.

A further survey (6) undertaken in 2013 by Independent Consultants, conducted interviews with 7 senior nursing staff at 5 of the 21 cancer centres. Interview participants were all in post prior to the introduction of the guidelines, oversaw their implementation and are currently managing the delivery of treatment regimens for children. Key findings from this survey showed that:

- When asked to rate the usefulness of the guidelines (scale from 1: no use at all to 10: very useful) the average score against the following four categories was: (i) evidence-based, 9.5; (ii) practical and implementable 8.5; (iii) clearly communicated, 8.5; (iv) clinically efficient, 8. One Centre commented that the guidelines pushed the perceived boundaries, resulting in greater patient comfort through the more acute treatment periods.
- When asked to score the benefits (scale from 1: no benefit; to 10: very beneficial) following adoption of the guidelines all of the criteria scored very positively, the average scores were: (i) general prevention/reduction of mouth sores, 8; (ii) patient comfort, 8; (iii) reduction in mouth infection, 7.5; (iv) reduction in hospital stay, 7; (v) reduction in medicines, 9; (vi) better mouth care/hygiene, 9. Several respondents stressed that a compromised mouth interfered with normal recovery processes due to patients not eating and drinking as they should.
- Those specialist cancer wards interviewed no longer prescribe Nystatin. Prior to the introduction of the guidelines this was routinely prescribed for all children undergoing cancer treatment except those with brain tumours. A course of Nystatin in children undergoing cancer treatment would typically be 4 doses per day every day for 3 out of every 4 weeks for six months. A bottle of 30ml of Nystatin (Non-proprietary) costs £15.44 (7) and will serve approximately 20 doses (5 days of treatment), so the average cost of Nystatin per child is £386. Cancer Research UK data (8) estimates that 1600 new cases of child cancer are diagnosed each year of which 25% are brain tumours, so about 1200 children would, prior to the introduction of the guideline, have had a course of Nystatin. Some children would have more than one course if treatment was prolonged through extra cycles. Based upon these figures, complete cessation of Nystatin treatment represents a potential minimum saving to the NHS of £463,000 per annum, £2.315 million over 5 years.
- Children receive better mouth care, oral pain is reduced, and the number of children returning to hospital for management of oral complications as a result of mouth infection between cancer therapies has reduced significantly. Staff interviewed for the survey suggested that re-admission due to complications of mouth infections has reduced from 10% of children to 5% since the guidelines have been in use, a reduction of 60 re-admissions per year. On average a re-admission is 2 days costing £1100. The guidelines have saved £66,000 per annum (£330,000 in 5 years) through reduced re-admissions as well as enhancing child and parent quality of life.
- A clear and immediate benefit described was the promotion and importance of normal oral hygiene and the subsequent translation of this in to the home environment through emphasising the cleaning of teeth and keeping the mucosa healthy for the child with cancer and the rest of the family.
- Interviewees spoke about “instant impact”, and the guidelines “got rid of any surplus medicines/treatments which were not good for the patient”. Respondents were unanimous that not using unpleasant tasting oral products with children was beneficial.
- Training and education of staff, supported by materials produced by the CCLG/RCN Working Group, assisted with dissemination, and enabled the risk stratification of oral care to have an impact: “no longer do clinicians prescribe what they ‘think’ is the right thing to use, and therefore only children who need additional care at the outset, such as BMT, receive it”.
- Education of parents has also been formalised, with staff mentioning use of guidelines with parents. “The guidelines were empowering…….informing parents on what to look out for/how to treat before it’s left too long and the child is required to go back in hospital for however long”.

The guidelines are in use throughout the UK and beyond. A 2013 workshop at the International Society of Paediatric Oncology conference held in Hong Kong revealed that delegates, from for example China, The Netherlands, Belgium, Sweden, USA and Canada were aware of the UK guidelines and they had informed more local guideline development work and thus influenced care internationally.

Gibson has continued to lead CCLG/RCN Working Group in gathering the research-based evidence and further refining the guidelines. The updated guidelines are expected to be released in 2014. In addition, Gibson has participated in many international projects related to mouth care, with respect to her internationally recognised expertise in this area (9-10).

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. CCLG/RCN Mouth Care Guidelines. Available at http://www.cclg.org.uk/treatment-research/guidelines
2. **Gibson F**, Bryan G, Clarkson J, Coulson C, Craig J, Khalid T, Kyriazidou A, Pizer B, Skinner R, Webster H, Worthington H, Glenny AM (2011) Influencing and sustaining change in oral care practices: experience of 10 years as a clinical study group. Abstract 648 (oral) 2011 International MASCC/ISOO Symposium, Athens, Greece, June 2011. *Journal of Supportive Care in Cancer*, 19, Supplement 2, S289.
3. East Anglia's Children's Hospices at http://www.each.org.uk/what-we-do/oral_care_forum/documents_and_resources/Guidelines_and_Best_Practice_Oral_Care_Cancer_and_Palliative_Care
4. BMJ Evidence Centre at http://bestpractice.bmj.com/best-practice/monograph/1135/treatment/guidelines.html (Note: this site requires a subscription, but can be accessed for 7 days as a free trial, so long as you have not had a previous recent free trial).
5. Craig JV, **Gibson F**, Glenny AM (2011) Audit to monitor the uptake of national mouth care guidelines for children and young people being treated for cancer, *Journal of Supportive Care in Cancer*, 19 (9), 1335-1341. DOI: 10.1007/s00520-010-0953-3.
6. Independent Consultants report (The Innovation Partnership 2013). Contact: Managing Director, The Innovation Partnership.
7. BNF for Children (BNFC) (2013) published by BMJ Group, London, ISBN: 978 0 85711 087 9, see entry for Nystatin on page 549.
8. Childhood cancer incidence in the UK, Cancer Research UK at http://www.cancerresearchuk.org/cancer-info/cancerstats/childhoodcancer
9. Tomlinson D, **Gibson F**, Treister N, Baggott C, Judd P, Hendershot E, Maloney AM, Doyle J, Feldman B, Kwong K, Sung L (2010) Refinement of the Children's International Mucositis Evaluation Scale (ChIMES): child and parent perspectives on understandability, content validity and acceptability, *European Journal of Oncology Nursing*, 14, 29-4. DOI: 10.1016/j.ejon.2009.10.004.
10. McGuire DB, Fulton JS, Park J, Brown CG, Correa ME, Eilers J, Elad S, **Gibson F**, Oberle-Edwards LK, Bowen J, Lalla RV on behalf of Mucositis Study Group of the Multinational Association of Supportive Care in Cancer/International Society of Oral Oncology (MASCC/ISOO) (2013) Systematic review of basic oral care for the management of oral mucositis in cancer patients. *Supportive Care Cancer*, 21 (11), 3165-77. DOI: 10.1007/s00520-013-1942-0.