ELSEVIER

European Journal of Cancer 40 (2004) 1217–1224

European Journal of Cancer

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A survey of current practice with regard to oral care for children being treated for cancer

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Received 9 September 2003; received in revised form 16 December 2003; accepted 13 January 2004

Abstract

The aim of the study was to establish current UK oral care practice for children with cancer. A telephone survey of all 22 United Kingdom Children's Cancer Study Group (UKCCSG) centres was undertaken. Nineteen (86%) of the centres reported using guidelines/protocols for mouth care. The use of routine preventive oral care therapies showed the greatest variation between centres. Four centres (18%) did not use any prophylactic oral care therapy other than basic oral hygiene, whereas seven (32%) routinely used a combination of three or more agents. Chlorhexidine was the most frequently administered prophylactic therapy (17/22 centres, 77%), followed by nystatin (11/22 centres, 50%). There was little variation in advice given to parents/patients on basic oral hygiene. Regarding dental check-ups, 9/22 centres (41%) recommended children to attend a hospital-linked dental clinic. Only at 8/22 centres (36%) did children undergo a dental check-up before commencing cancer treatment. The survey identified significant variation in preventive oral care therapies and dental check-ups at the UKCCSG centres. Attention needs to be given to establishing evidence based, effective strategies.

Keywords: Oral hygiene; Dental health surveys; Child; Adolescent; Child, preschool; Chemotherapy; Radiotherapy; Mouth diseases

1. Introduction

Treatment of childhood cancer is becoming increasingly effective, with survival rates for childhood cancers reported at 70–75% in parts of Europe and North America [1]. Despite advances in chemotherapy and radiotherapy, cancer treatment still remains associated with clinically important, sometimes dose-limiting, side-effects. Oral complications, occurring during and after cancer treatment, are common and can cause pain, difficulty in swallowing and phonation, and poor nutrition. They clearly can impact severely on a patient's quality of life [2].

One of the most common side-effects of cancer treatment is mucositis, a painful inflammation and ulceration of the mucous membrane. The oral mucosa consists of rapidly dividing cells that are especially susceptible to the damaging effects of cytotoxic therapy. Oral complications during chemotherapy and radiotherapy can arise from direct injury to the oral mucosa, but they also result from cytotoxic myelosuppression producing profound neutropenia [3]. The prevalence of chemotherapy-induced oral mucositis has been shown to range from 30% to 75% of patients, depending upon treatment type [4,5]. Mucositis may predispose a child to fungal infections (most commonly candidiases), viral and bacterial infections, which may then lead on to life-threatening systemic

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0959-8049/$ - see front matter © 2004 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2004.01.030

infections. Additional oral complications following cancer treatment include xerostomia due to dysfunction of the salivary glands and post-irradiation dental caries. Depending upon the age of the child at the time of cancer treatment, developmental defects involving the teeth are also of concern and can impact on the child's quality of life and future dental treatment needs.

The careful oral management of children treated for cancer can improve quality of life during treatment. However, there is 'confusion and conflict' surrounding what constitutes appropriate mouth care [3], and at present no clear guidelines exist outlining the optimal oral care strategy for patients. A wide variety of interventions are used for both prevention and treatment of oral complications, only some of which have been shown to be effective [6–11]. The United Kingdom Children's Cancer Study Group (UKCCSG) and the Paediatric Oncology Nursing Forum (PONF) have established a subcommittee to investigate mouth care and are currently developing comprehensive, evidence-based guidelines to aid decision-making in this area. Without such guidelines, and with an apparently ever-increasing choice of preventive and therapeutic interventions, consistency of care across cancer centres is unlikely. The aim of this study was to conduct a telephone survey of centres within UKCCSG to identify current practice regarding oral care of children being treated for cancer.

2. Methods

A structured questionnaire was developed and piloted by members of the UKCCSG Mouth Care Group. The questionnaire was designed to be used over the telephone, taking approximately 15–20 min to complete. Five main themes were explored using a mix of open- and close-ended questions. An outline of information recorded for each theme is presented in Box 1.

Box 1. Themes explored within the survey

Existing guidelines and protocols
- Use of any published or locally developed (verbal or written) guidelines/protocols
- Content of the guidelines
- Target audience
- Consistency of application
- Availability of parent/patient information leaflets

Oral care
- Staff responsibility for oral care
- Instructions provided to patients/parents regarding basic oral hygiene
- Routine preventive therapies
- Variations in oral care according to type of cancer treatment
- Provision of oral hygiene products
- Use of oral assessment scales or instruments
- Review of oral care regimen

Dental check-ups
- Advice given to patients/parents regarding dental visits
- Dental check-ups before commencing cancer treatment
- Contact with dental hygienist
- Follow up or continuing care after treatment completion

Teaching and research
- Inclusion of oral care in staff education programmes
- Ongoing oral care research/audits

Evidence based guidelines
- Attitudes towards evidence-based guidelines

A letter was posted to all of the nurses, within the 22 UKCCSG centres, who act as a 'link' between the Paediatric Oncology Nursing Forum (PONF). The letter outlined the aim of the survey and the issues to be covered in order to give the potential interviewee time to reflect on oral care practice within their centre. The nurses were subsequently contacted by telephone to arrange a convenient time to undertake the telephone interview. If they were unable to help with the survey, they were asked to provide contact details of another member of staff at their centre who would be able to assist.

All telephone interviews were conducted by the same interviewer (AMG) and data collected entered into *SPSS* (version 10.1 for Windows). Responses from open-ended questions were tabulated. A copy of the completed questionnaire for each centre was sent to the interviewee for their records. If they had additional information to add, or felt the interviewer had misinterpreted their responses, they were asked to contact the interviewer. Copies of all national/international guidelines and locally developed guidelines and protocols used in each centre were requested, as were any available patient information leaflets. An addressed envelope was provided for these returns.

3. Results

A member of staff from each of the 22 centres contacted was available for interview. All those interviewed were nurses, although their grades/designations varied between centres.

3.1. Existing guidelines and protocols

Nineteen (86.4%) of the centres reported using published or locally developed guidelines/protocols for mouth care, 17/19 (89.5%) being written as opposed to verbal. A majority of the interviewees felt that their guidelines were applied consistently for all patients within their centre (13/19, 68.4%). Reasons for variation in the application of guidelines included child compliance, consultant preference, staff awareness and time constraints. One interviewee reported that the guidelines used in their centre had been updated 1 year previously and that time was still needed for them to be adopted by all staff. Patient/parent information leaflets were available from 16/22 (72.7%) of the centres.

Oral assessment was addressed in 13/19 (68.4%) and prevention/treatment addressed in 16/19 (84.2%) sets of guidelines. Fig. 1 illustrates those for whom guidelines were produced and those who act upon them. It appears that the most frequent 'target audience' for oral care guidelines within the UKCCSG centres were nurses (17/19, 89.5%), oncologists/medical staff (14/19, 73.7%) and parents/patients (10/19, 52.6%). A similar pattern was shown when the interviewees were asked who they felt actually acted upon the guidelines, suggesting that the appropriate personnel were using the guidelines.

3.2. Oral care

Only 5/22 centres (22.7%) had a designated member of staff responsible for oral care issues, in each case a nurse. Five centres (22.7%) had a structured group addressing/implementing oral care (one centre had both a designated member of staff and a group). The combinations of staff involved in the structured groups are presented in Table 1. Surprisingly, only one centre included a dentist within their group and none involved a dental hygienist or a dietician.

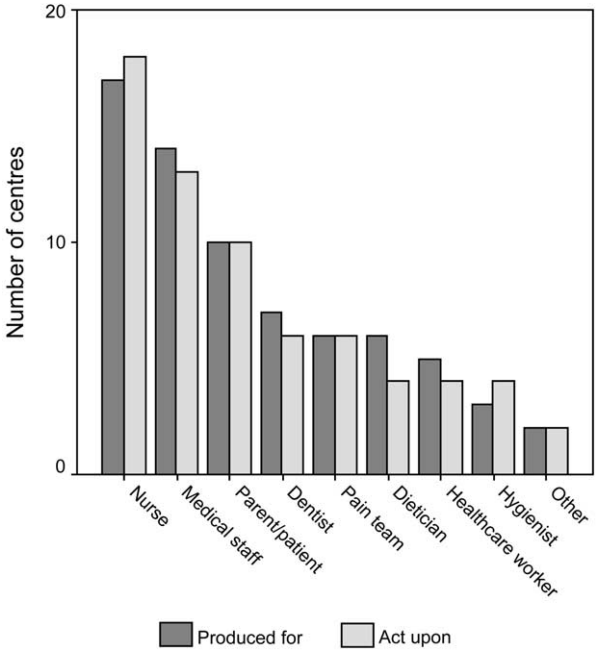

Fig. 1. Personnel for whom guidelines are produced, and who implement them.

When asked about what instructions were given to parents/patients with regard to basic oral hygiene, 20/22 (90.9%) of the centres recommended using a soft toothbrush. The recommended frequency of brushing varied, with a minimum of twice a day. Less than half of the centres (10/22, 45.5%) specified the use of fluoride toothpaste. Only 8/22 centres (36.4%) provided care-of-toothbrush instructions, such as not sharing toothbrushes with other members of the family, keeping the toothbrush dry and separate from others and replacing it frequently (this ranged from every 6 weeks to every 3 months). One centre was exploring the use of boiling toothbrushes after each use for high-risk patients, such as those with prolonged neutropenia.

Fig. 2 shows the number of centres routinely using nystatin, fluconazole, chlorhexidine, Difflam and ice chips as prophylactic mouth-care therapies. Seven centres (31.8%) used a combination of three or more agents routinely. The most frequently used prophylactic therapy was chlorhexidine, with use varying between twice and four times per day. Several centres discussed having a choice of methods available (mouthwash (0.2%, 5–10 ml), spray, gel or on pink sponges) to improve compliance. Two centres recommended diluting the chlorhexidine if preferred by the patients. In contrast, one centre clearly stated that the chlorhexidine should not be diluted as that could impact on effectiveness. Eleven centres prescribed nystatin as a prophylactic antifungal mouth-care therapy. Dosage ranged from 1 ml to 5 ml, with the frequency of administration typically three to four times a day. One centre reported using nystatin 3-hourly if an oral infection was suspected. The nystatin was usually administered as a suspension to be 'swished and swallowed'. One centre specified sugar-free suspension, but this was reported to be poorly tolerated by another centre. Lozenges were sometimes used if the suspension was not tolerated. The recommended gap between taking the nystatin and eating, drinking or

Table 1
Staff included in structured groups addressing oral care

	Centre 2	Centre 10	Centre 12	Centre 17	Centre 18
Nurse	√	√	√	√	√
Oncologist/medical staff		√	√		√
Dentist	√				
Pain team	√	√			
Practice educator	√				
Pharmacist	√		√		
Ward manager				√	

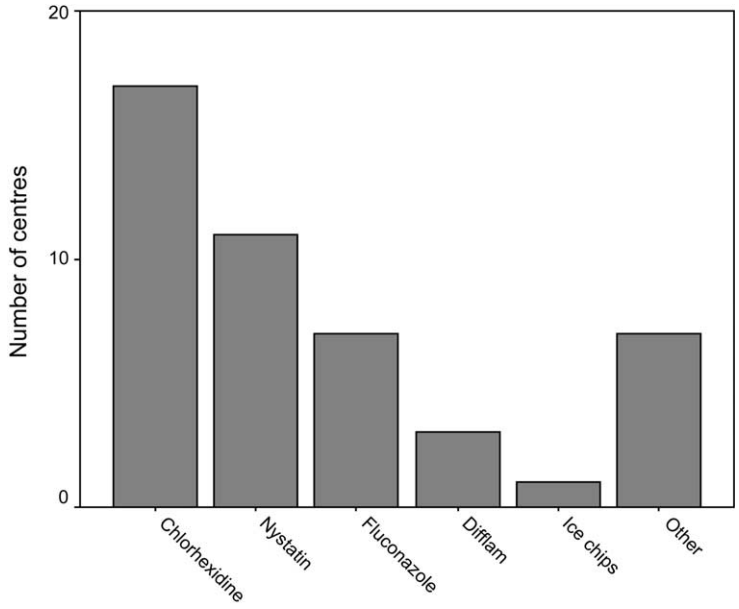

Fig. 2. Number of centres routinely using preventive mouth-care therapies.

using chlorhexidine varied from 15 to 40 min. Fluconazole was reported to be used routinely as a prophylactic measure in seven centres (31.4%). In four of these centres, it was only prescribed as a prophylactic measure for high-risk patients (for example those receiving treatment for acute myeloid leukaemia) or those who could not tolerate nystatin or chlorhexidine. Sucking ice chips was recommended by one centre, although difficulties in producing sterile ice chips were raised by two interviewees. Other therapies reported as being used routinely included itraconazole, folinic acid (for patients receiving methotrexate), miconazole gel and selective decontamination of the digestive tract (consisting of tobramycin, colistin, amphotericin).

Four centres (18.2%) did not use any preventive mouth-care therapy as a routine measure. Seventeen centres (77.3%) would alter the oral care instructions and therapies provided if the patient had established oral problems, such as a sore mouth.

Instructions on oral care were usually given to families in the first instance by a nurse (at 20/22 centres, 90.9%). Similarly, during treatment it was most frequently the nurses who continued to provide instructions on oral care (20/22, 90.9%), although in certain centres oncologists (5/22, 27.7%), dentists (2/22, 9.1%) and dental hygienists (3/22, 13.6%) also gave instruction. Fifteen of the centres (68.2%) were able to provide oral hygiene products (typically toothbrushes and toothpaste) for patients, if required.

In 14/22 centres (63.6%) a child's oral care regimen would always be reviewed at discharge. Fig. 3 shows the frequency of those activating change to the child's oral care regimen. A number of reasons were reported for changing the regimen including individual mouth-care assessment, presence of pain, compliance and/or tolerance with previous plan, neutrophil count, need for dental treatment and diet.

Sixteen centres (72.7%) reported using an oral assessment scale, 11 of which were modifications of the Eilers OAG [12]. Interviewees from all 16 centres using an oral assessment scale reported that the scale was primarily used by nursing staff. Other personnel reported as using oral assessment scales were oncologists (7/16, 43.8%), dental hygienists (1/16, 6.3%), dentists (1/16, 6.3%), health-care assistants (1/15, 6.3%), and members of a pain team (1/15, 6.3%). In three of the centres using an oral assessment scale, the scale was available for use by parents (18.8%). The frequency of use of the oral assessment scales after initial assessment at diagnosis varied in 13/16 (81.3%) of the centres. Reasons given for the variation included existing problems for individual patients, onset of pain, compliance, shift patterns, staff and time restrictions.

3.3. Dental check-ups

In only three centres (13.6%) was it reported that advice on dental visits was provided by either a dentist or dental hygienist. In all other centres, advice was provided by either nursing or medical staff (or both).

In nine centres (40.9%) the interviewee reported that at the time of diagnosis of cancer, children were recommended to attend a dental clinic linked to the hospital as opposed to their local general dental practitioner (GDP). Ten centres advised children to continue visiting their GDP for regular, 6-monthly check-ups but for the GDP to liase with the cancer centre if need for interventional

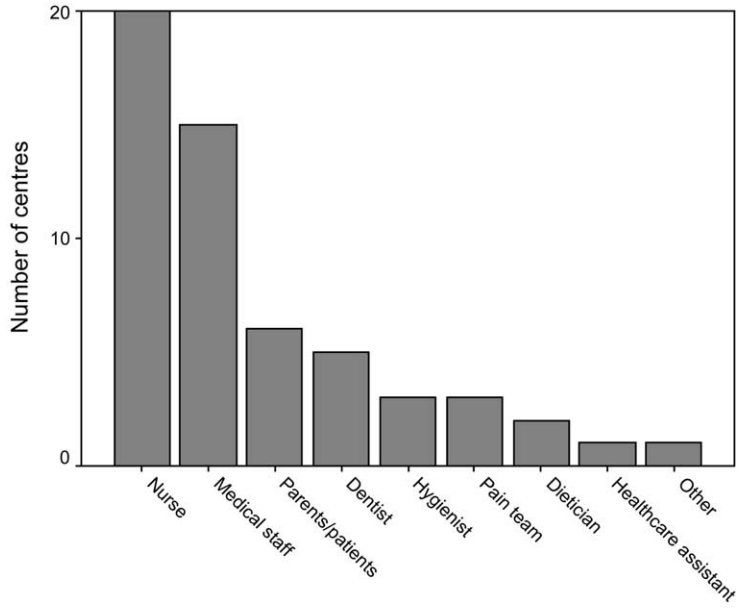

Fig. 3. Personnel activating changes to the child's oral care regimen in participating centres.

dental treatment was identified. At approximately one-third of the centres children underwent a dental check-up before commencing cancer treatment. At two of these centres children also saw a dental hygienist. One additional centre ensured that children see a dental hygienist before cancer treatment, but not a dentist.

At 20 of the 22 centres (90.9%) children were referred back to their GDP for all continuing oral management after completing cancer treatment unless the patient: (1) was continuing to attend hospital for 3- to 6-monthly follow-up appointments (one centre); (2) was post marrow transplantation (one centre); (3) was persistently neutropenic (one centre); (4) was an outpatient and dental treatment needed (two centres); and (5) had persistent problems (two centres). One interviewee reported that at their centre, advice regarding dental check-ups after completion of cancer treatment varied according to type of treatment received. At one centre no specific advice was offered.

3.4. Teaching/research

Oral care was addressed in the nursing staff's education programme at 21/22 of the centres (95.5%). The content of the training material was known to be reviewed regularly in 14/21 (66.7%) of these centres. With regard to the medical staff's education programme, a majority of the interviewees (14/22, 63.6%) were unable to comment on whether or not oral care issues were addressed in training. Two (9.1%) stated that oral care was definitely not covered.

Four of the centres had continuing oral research projects (two centres developing care pathways; one centre evaluating the Oral Assessment Guide; one centre had a member of staff undertaking a dissertation on mouth care).

3.5. Evidence based guidelines

All interviewees stated that they would value nationally developed, evidence-based guidelines. Themes arising from this issue included the awareness of variation between centres, the need for more formalised education on oral care, and the development of standards across all oncology centres, provided that there was still some scope for local adaptation.

4. Discussion

It has been well documented that telephone surveys are associated with high response rates [13] and this is supported by the fact that all 22 UKCCSG centres participated in the current survey. It should be acknowledged in the interpretation of the findings that the responses obtained were from a single member of staff at each centre, and may not be an accurate reflection of the views of all staff.

The survey identified some diversity in the oral care provided to children and young people being treated for cancer in the UK. Indeed, there was even reported variation in mouth care within six centres where oral care guidelines did exist and, while some of this variation is due to patient preference and adherence with the oral care routines, consultant preference, staff awareness and time constraints were also reported as affecting the mouth-care advice and treatment provided.

The use of routine, preventive oral care therapies was the area with the greatest variation between centres.

Four centres did not use any prophylactic oral care therapy, other than vigilant basic oral hygiene, whereas seven centres used a combination of three or more agents routinely. Recent systematic reviews have identified potentially effective interventions for the prevention of both mucositis and candidiasis [6,8]. For mucositis these interventions include allopurinol, granulocyte-macrophage-colony-stimulating factor and povidone mouthwashes, topical antibiotics and lozenges, hydrolytic enzymes, and amifostine. The strength of evidence supporting these interventions varies and the benefits for patients with different cancer types is, as yet, unknown. There is strong evidence, however, that for the prevention of candidiasis in patients receiving cancer treatment, only drugs absorbed (e.g. fluconazole, itraconazole, ketoconazole) or partially absorbed (e.g. clotrimazole, miconazole) from the gastrointestinal tract are effective [6].

The survey identified chlorhexidine as the most frequently administered prophylactic therapy, used in 17 of the UKCCSG centres, given up to four times a day. No benefit for chlorhexidine in the prevention of mucositis or candidiasis has been demonstrated in the research literature [6,8]. Half of the centres interviewed routinely used nystatin to prevent candidiasis, despite several of these centres stating that they were aware that the use of nystatin as a prophylactic therapy was not supported by research evidence [6,14]. Nystatin has not been recommended for use in neutropenic cancer patients since 1995 [15]. Fluconazole is less frequently used as a routine prophylactic measure and sometimes only as a second choice where nystatin and/or chlorhexidine are not tolerated. This result is perhaps surprising when the research evidence is taken into account, showing fluconazole to be effective at preventing invasive fungal infections [6,14]. That the centres continued to use nystatin illustrates the difficulty in bridging the gap and changing practice in response to research evidence. Strategies to promote the implementation of research-based recommendations need to be explored [16].

There was little variation in the advice given to parents/patients on basic oral hygiene. The research evidence to support an optimal oral hygiene routine for paediatric oncology patients is limited, and a 'common sense' approach may have to be taken with regard to certain aspects, drawing upon evidence from other populations. All centres recommended regular tooth brushing, with a minimum of twice-daily brushing. Over 90% of the centres suggested the use of a soft toothbrush but fewer than half specified the use of fluoride toothpaste, despite the benefits of fluoride toothpaste being well documented [17] and the increased risk of caries associated with xerostomia [18,19]. One centre discussed leaving the choice of toothpaste to the patient, but did encourage brushing, as they felt that adherence with brushing was more important than the use of fluoride toothpaste.

Parent/patient information leaflets were distributed at 72.7% of the UKCCSG centres. Such leaflets can empower patients/parents, and may lead to a better understanding of what to expect and why. The provision of information leaflets may also improve patient compliance [20]. It is encouraging that so many centres provide information on mouth care in the form of a leaflet/booklet. Written information, as well as complementing verbal advice, has been shown to alleviate anxiety and improve patients' knowledge and satisfaction with information received [21,22]. The content of the patient information leaflets available currently reflects the variation in practice between centres. It is recognised that changes in practice may warrant changes to documentation including patient information leaflets. The development of appropriate patient information leaflets requires considerable time and resources, and may act as a potential barrier to change.

It has been suggested that the oral management of children receiving treatment for cancer requires a team approach [23]. Members of such a team may include the paediatric oncologist, nursing staff, dentist, dental hygienist, dietician, members of the pain team, pharmacist and the patients/parents. The results of the survey indicate that oral management is the responsibility of nursing staff more than any other personnel. Nurses are the key staff involved in providing advice on basic oral hygiene and preventive measures both at diagnosis and throughout treatment. The oral assessment scales used in over 70% of the centres are used primarily by nurses and, along with medical staff, nurses are more likely to provide advice on dental visits than a dentist or dental hygienist. Despite the promotion of partnership between medical, nursing and dental professionals, only one centre included a dentist in a structured group for addressing mouth-care issues. However, it may be that other centres, lacking a formal mouth-care group, do still have a high level of cooperation and discussion between different health professionals.

Oral care was reported to be addressed in all but one of the centres' nursing staff's education programmes. However, the education was not always classed as formal education and was not always regularly reviewed. For example, one centre reported that oral care was covered on a staff orientation day only. If nurses are to play such a major role in the provision of oral care, there is a need for continuing education, ideally in collaboration with dentists [24].

Collard and Hunter question the ability of health professionals other than dentists to conduct oral assessment and diagnose a range of oral pathology [25]. It is optimal for the initial assessment of the mouth, at the time of the diagnosis of cancer, to be conducted by a dentist in order to identify existing dental disease [25,26]. By treating dental disease early, the risk of oral infections during cancer treatment may be reduced [25]. However, as

the survey illustrates, this only occurs in around a third of the UKCCSG centres. Possible reasons for children not being seen by a dentist before commencing cancer treatment are lack of time, resources and awareness of the importance of the initial oral assessment. Nineteen of the centres advise patients to visit dental clinics linked to the hospital for regular check-ups, or recommend the child's GDP liases with the cancer centre if the need for dental treatment is identified. A previous study identified 16 UKCCSG centres as being able to carry out operative dental procedures for children on site [25]. The authors highlighted the importance of appropriate dental services at tertiary referral centres.

The importance of oral care for children being treated for cancer appears to be acknowledged by UKCCSG centres. Over 85% of the UKCCSG centres have written guidelines or protocols for mouth care. This figure is slightly higher than that recorded in a previous survey of the UKCCSG centres, focusing on oral and dental care in acute lymphoblastic leukaemia [25]. The increased use of guidelines is encouraging as they can assist clinicians and patients in appropriate decision-making [27]. The potential benefits of guidelines include improved patient care, consistency of care, the promotion of interventions of proven benefit and the reduction in use of ineffective, or potentially harmful practices [28]. However, for these benefits to be achieved, recommendations provided by guidelines must be explicit and, ideally, based on sound, scientific evidence. The attitude of interviewees towards the development of national, evidence-based guidelines was positive. The results of the survey are currently being used to inform the production of evidence-based guidelines for oral care for children being treated for cancer. The guidelines are being produced by a multidisciplinary team and aim to establish the most effective oral care strategies, as indicated by the best available research evidence.

5. Conclusion

The survey identified variation in oral care practice between UKCCSG centres, particularly with regard to preventive therapies and dental check-ups. Attention needs to be given to establishing the most effective oral care strategies for children undergoing cancer treatment. The results of the survey will be used to inform the development of evidence-based guidelines, drawing on the best available research evidence.

Acknowledgements

The authors would like to thank all the nurses who participated in this survey (Rosie James, Wendy Doorghen, Barbara Carlisle, Jeanette Hawkins, Ruth Elson, Rachel Coyne, Alice Ward, Martina Nathan, Joanne Kemp, Karen MacFarlane, Rachel Hollis, Debbie Jackson, Julie Bayliss, Deborah Morton, Hina Mistry, Danine Pasquill, Sandra LaCore, Helen Inskip, Angela Houlston, Karin Newton, Sally Coole, Jane Mallinson).

Members of the UKCCSG-PONF Mouth Care Group are: Barry Pizer (Chairperson), Consultant Paediatric Oncologist, Alder Hey Children's Hospital, Liverpool, UK; Liz Auld, Paediatric Oncology Research Nurse, Manchester Children's Hospital, Manchester, UK; Jan Clarkson, Senior Lecturer in Dental Primary Care, Dental Health Services Research Unit, University of Dundee, UK; Suzanne Coulson, Paediatric Oncology and Haematology Unit, Sister, St James' University Hospital, Leeds, UK; Jean Craig, Research Associate, Alder Hey Children's Hospital, Liverpool, UK; Monty Duggal, Professor of Child Dental Health, Leeds Dental Institute, Leeds, UK; Tim Eden, Cancer Research UK, Professor of Paediatric Oncology, Central Manchester and Manchester Children's University Hospitals and the Christie Hospital, Manchester, UK; Faith Gibson, Lecturer in Children's Nursing Research, Great Ormond Street Hospital, London, UK; Anne-Marie Glenny, Lecturer in Evidence Based Dentistry, University Dental Hospital of Manchester, UK; Mabel Slater, Head of Unit of Oral Health Sciences, University Dental Hospital of Manchester, UK; Helen Worthington, Professor of Evidence Based Care, University Dental Hospital of Manchester, UK.

The UKCCSG Mouth Care Group are grateful for funding received from Cancer and Leukaemia in Children (CLIC).

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