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Long-term follow-up following childhood cancer: maximising the contribution from nursing

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1. Introduction

As more children are now cured of their cancer, increasing attention is being focused on the long-term sequelae of the disease and its therapy from a holistic rather than solely a physical point of view. Every member of the family is affected by a diagnosis of cancer and the experience of living with a chronic disease. Families play a crucial role in achieving and maintaining long-term survival. A comprehensive long-term follow-up programme is important in monitoring and supporting the patient and their family. Currently, the contribution by nurses to the follow-up of patients varies. By re-considering the current approaches to follow-up, opportunities to maximise the contribution of nurses will be revealed.

The aim of this paper is to review follow-up care in the United Kingdom (UK) and suggest any modifications that may be needed. This approach should maximise the role of the nurse within the multidisciplinary team. This review starts by outlining the current approach for follow-up care offered to children/young people who have survived childhood cancer in the UK. The paper then explores what lessons can be learnt from the United States of America (USA), where the role of the nurse in long-term follow-up has been established for many years, and how these can be adapted to the specific needs of both children/young people and health care professionals in the UK. It is hoped that rather than re-inventing the wheel, the proposed outline can be based on current best practice and utilise available guidelines as frameworks to develop a cohesive strategy in meeting the needs of this growing population of children and young people.

2. Survival following childhood cancer

Within the UK, over two-thirds of children diagnosed with cancer can expect to survive their disease; giving rise to the much quoted figure of 10 000 adult survivors of childhood cancer in this country, a total which increases by more than 500 each year [1]. For many lay people and healthcare professionals the end of treatment for childhood cancer is a time of celebration; at last the 'nasty' side of things is over and the child and family can return to some semblance of normality. Passing 5 years free of disease is another celebrated milestone as the child is often considered to be cured of their cancer [2].

However, for healthcare professionals involved in the care of children with cancer and their families, it has been apparent for nearly 50 years [3] that not all the children who have reached the end of their treatment for their disease will have survived in the holistic sense of the word. For the child and his family, at least three aspects of their lives will have been affected in some way: biological, psychological and social [4]. Each of these aspects will together or separately influence the quality of life for children and adults within the family.

As more children are cured of cancer, increasing attention has focused on the so-called late effects of therapy [5], both physical [6,7] and psychological [8,9] outcomes that may impact on the quality of life of survivors [10]. Although described as 'late', for some children the chronic effects of their disease and/or its treatment may be apparent during or soon after the completion of treatment. Late effects are therefore defined herein as persistent adverse changes related to the disease, its treatment or both. Where previously surveillance of the survivors of childhood cancer was mainly based on the evaluation of physical outcomes, the consequences for social and emotional adjustment are now increasingly being addressed [11–13] with the

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aim of making the transition to 'normal life' easier post-treatment [3].

3. The needs of the child/young person and their family after treatment

The psychological implications of childhood cancer were first seriously acknowledged by Koocher and O'Malley [14], and have since been the focus of others' work [15,16]. Within the body of evidence on this subject, there appears to be a consensus that true psychopathology is rare though the degree of psychological damage varies from mild to severe [4]. Just as varied are the suggestions as to how to apply some sort of objective measurement to such a subjective area. Jenney and colleagues [11] suggest a generic multidimensional measure for use in survivors in whom social and psychological evaluation of well-being is included alongside physical measures such as cognition, sexuality and activity (see also the discussion in the forthcoming Paediatric Update on the Quality of Survival by Meriel Jenney). The use of a generic model may be valuable in gauging the overall well-being of the child/young person. A unified approach such as this may also go some way to meeting the complex needs of this disparate group of patients. A group in which those who were treated for cancer at an early age may be at greater risk of physical sequelae and those treated as older children/young people are at more risk of psychological sequelae [11].

More recently, the social effects of disease and treatment among childhood cancer survivors have also become apparent [15,16]. Issues such as changes in relationships, low self-esteem and difficulties in gaining employment are commonplace [17], although there is some emerging reference to childhood cancer survivors reporting positive outcomes from their experience [18]. The support offered to the survivors is often described as multiprofessional, a sensible rubric given the variety of needs and agencies involved. What does seem to be missing, though, is a sense that one professional is involved with each survivor's needs and care. The exception to this would appear to be the role of the nurse in re-integration into school, an important consideration for a truly cured child [2].

For most of those children and young people who are the subject of this paper, it is the difficulty in coping with mainstream education that will impact not only on their future employment prospects, but also their levels of self-esteem and sense of worth [19]. The difficulties are most marked for children treated for central nervous system (CNS) tumours or those receiving cranial irradiation [20]. Findings highlight the need for assistance in the re-integration into schools and the need to aid survivors and their families in accessing available support systems [21]. The role of the nurse in establishing re-entry into school programmes has been described in both the UK and North American literature [21,22]. Both these studies describe the benefits of structured and continuing intervention. Such intervention is felt to reduce the anxiety of mothers and teachers and to smooth the social transition back into the child's peer group [21]. Whilst structured programmes are still rare in the UK, community nurses often facilitate similar informal programmes, although the evaluation and co-ordination of the current informal programmes is missing.

In response to a lack of co-ordination in care, in 1995 the United Kingdom Childhood Cancer Study Group (UKCCSG) published guidelines for follow-up care [23]. These are now an established part of childhood cancer care and recommend follow-up for life, with children/young people continuing to be seen by their paediatric haematologist/oncologist. These guidelines advocate that members of the multi-professional team, which involves other specialists, including paediatric endocrinologists, cardiologists, psychologists and nurses, follow-up children/young people. However, even with available guidelines and protocols, designed for use in the outpatient setting to guide appropriate surveillance, follow-up varies within the 22 UKCCSG centres in the UK. On the whole, there is little consensus on how follow-up should take place. This results in inconsistencies in care in the UK and elsewhere [24], perhaps because little is known about the resources appropriate to help families in the re-adjustment to 'life after treatment'.

The completion of treatment for cancer brings with it both hope (of a lasting cure) and fear (of relapse) [25] although it may be that, as the experience of childhood cancer unfolds, these two emotions can be accommodated into a balanced perspective [25]. Help may be needed towards this goal, but it is notable that we found only one study in which the views of the survivors themselves had been taken into account [26]. The issue at stake is the provision of service to identify the appropriateness of an approach in meeting their physical, psychological and social needs. This may be due, in part, to the cognitive age of the group involved but, as survivors move towards adolescence and adulthood, in the age of patient-centred care, such consultation would seem appropriate and an area that must be given serious consideration [27].

If follow-up services are to deliver patient-centred care, should not the children and their families who will use these services be asked what services they want and what to expect from them? At present, this kind of consultation seems to be lacking. Moreover, in one study, a cancer survivor described feelings of being patronised by healthcare professionals rather than having her fears acknowledged and validated as a normal consequence of surviving a life-threatening illness [28].

The same survivor later stated she was unwilling to burden the physician who had asked her questions that seemed irrelevant when compared with the issues of those patients that were still receiving treatment for their disease. This predicament must be common to many of the survivors of childhood cancer and their physicians in the UK today. The way forward, advocated by many [29,30], is a multiprofessional approach involving healthcare professionals specifically assigned to the issues surrounding survivorship of childhood cancer.

4. Decisions about follow-up: who and how, a UK perspective

The general belief among paediatric oncologists is that all survivors of childhood cancer should be followed-up for life [31]. However, in the absence of evidence to support the view that follow-up has an impact on survival and quality of life, with an ever increasing number of long-term survivors, concern has been raised over the costs of providing this service [32]. In addition, the children/young persons themselves may question the benefit of repeated clinic visits, as the relevance of follow-up care may lessen as the distance from diagnosis lengthens and the reasons for attending clinic become unclear. It is vital, therefore, to ensure that the care and information given at the clinic continues to be seen as appropriate and useful [26]. Additionally, follow-up for long-term survivors must at some point encompass adult cancer services, with a period of overlap between paediatric- and adult-based services [33]. This transition is necessary to meet the changing requirements of survivors [34] and should be introduced to families early in their follow-up care. This would allow children/young people and their families' time to become accustomed to the idea and for age-appropriate healthcare to be afforded to survivors throughout their lifetime. However, not all survivors of childhood cancer require the same level of intervention from their primary, secondary or tertiary healthcare teams, nor do all these teams need to be involved with every survivor.

Healthcare professionals in the UK are facing a challenge to consider the 'who' and 'how' of long-term follow-up for the following reasons:

- Relevance of follow-up to children and young people
- Relevance of follow-up to physicians
- The need for co-ordinated transition to adult services
- Lack of evidence supporting a change in outcome for long-term survivors
- Impact on quality of life
- Appropriate use of finite resources.

It is these issues that provide an opportunity to consider alternatives in follow-up practice, to improve the current service in a more cost-effective and patient-centred way.

In order to address these issues, two fundamental questions must be answered. Firstly, are there some children/young persons who can be discharged from follow-up and never be seen again? And secondly, for those children/young persons who do require follow-up, who is the best person to provide that care and in what setting? These questions need to be asked within the context of the purpose of follow-up, distinguishing between the need for scientific research and clinical follow-up, which could be considered to provide more noticeable benefit to survivors. For the survivors, follow-up must be meaningful, enabling the child/young person and parents to be vigilant, but not overly alarmed, about potential late effects [35].

In answer to the first question, paediatric and adult oncologists must debate the benefit of follow-up and identify criteria for survivors who will need long-term follow-up and those who will not. It is generally accepted that not all survivors of childhood cancer need the same intensity of follow-up [36]. The level of intervention is dependent on the factors shown in Table 1, as well as the individual needs of the child and family. It has also been suggested that healthcare professionals involved in the child and family's care may also influence the level of intervention [33]. The debate about who receives follow-up could then result in some creative thinking about who is the most appropriate person to provide follow-up and in what setting. An evaluation of the current service would result in changes that are based on patient and family need and not on tradition. For example, surveillance may be continued by increasing contact with the primary-care provider [36], postal or telephone follow-up, regular contact by phone [32] or by introducing nurse practitioners [37] and nurse-led clinics [35].

Complementary to the tradition of physician led follow-up, there are already examples in the UK of nurses playing a key role in this aspect of care. A postal questionnaire of the 22 UKCCSG centres (completed in December 2000), with responses received from 20 centres, revealed a range of approaches to nurse-led follow-up that included three centres undertaking this by post, and three centres using a telephone follow-up. Currently, there is only one nurse-led clinic (only for bone marrow transplantation). However, five centres have employed a nurse with a responsibility for long-term follow-up, with two centres stating that such a role was being undertaken by clinic nurses with an interest in long-term follow-up. The profile of the nurses in the five centres who have follow-up as their main area of responsibility does vary in relation to education preparation, clinical experience and clinical grading (sal-

Table 1
Factors influencing the level of follow-up following treatment for childhood cancer

Type of cancer
Location and extent of disease on diagnosis
Type and intensity of treatment modalities used in the treatment of the cancer
Age, as well as the physiological and developmental status of the child at diagnosis genetic/familial predisposition that may interact with long-term effects

Source: Ref. [56].

ary), and this is consistent with specialist roles throughout nursing in the UK [38]. Local need will always play an important role when decisions are being made about how significant the nursing contribution is to long-term follow-up. None the less, there is evidence from the USA that nurses often take the lead in long-term follow-up and are key workers for children and families, while remaining firmly within the context of multiprofessional care [39].

5. Nurse-led follow-up clinics: lessons from the USA

Nurse-led follow-up clinics have been in existence in the USA since 1983; the first in Philadelphia was coordinated by a paediatric nurse practitioner specialised in oncology [40]. This post represents one approach to nurse-led follow-up care. The focus for follow-up in this initial programme was to provide comprehensive and systematic evaluation and treatment and to:

- Decrease the full impact of long-lasting effects of treatment
- Assist the survivor and family to cope effectively while monitoring and treating late effects
- Help the survivor and family gain perspective on the cancer experience so that they can be vigilant toward potential late effects.

Over time, through publications, presentations at conferences, education programmes and discussion amongst the many nurses now undertaking this role, the sphere of clinical practice has been refined and expanded upon. The autonomy that the role facilitates and encourages has enabled the role to evolve in a fashion consistent with trends described for advanced nursing practice in general [41,42]. The primary focus of the role "flows from direct care of individual survivors and high-risk sub-groups to indirect care of the clinic population of survivors as a collective and of the community at large" [36]. The role encompasses the key components of: speciality care-provider, educator, clinical programme manager, researcher and consultant (Fig. 1) and blends the role of the clinical nurse specialist (CNS) and nurse practitioner (NP) [43,44]. This blending of the CNS and NP roles ensures that the goals of improving the quality of nursing care to patients, providing a full range of primary healthcare services, such as undertaking physical assessments, making nursing as well as medical diagnoses, referring and prescribing investigations and treatments, are achieved [45].

6. Developing the nursing role within long-term follow-up in the UK

The approach described by Hobbie and Hollen [36] is one potential way of maximising the nursing contribu-

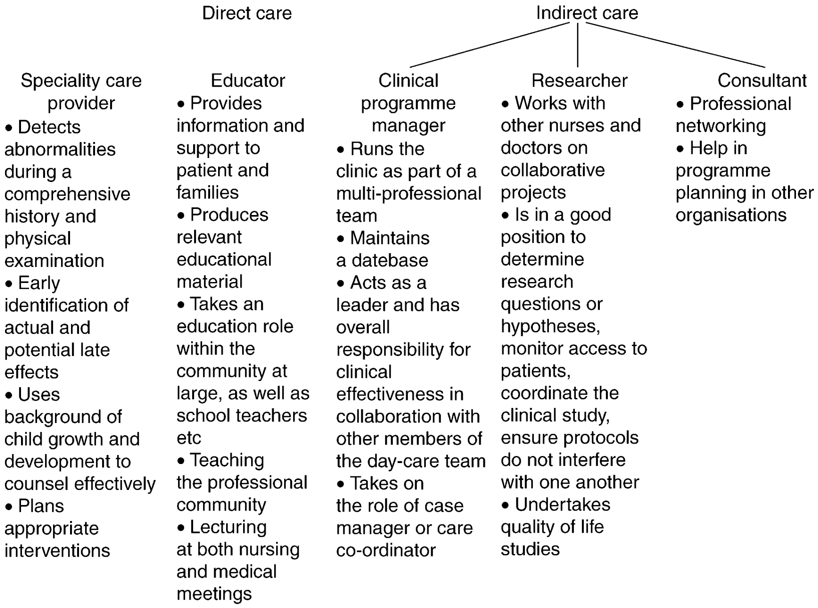


Fig. 1. Role of the paediatric nurse practitioner in long-term follow-up.

tion to follow-up. However, there is also an opportunity to choose two separate roles, that of the clinical nurse specialist or nurse practitioner, depending on the needs of the service. These roles are well defined in the USA and, although less well defined in the UK, experience added to understanding gained from the USA and other countries can help to develop these roles [46,47]. The consultant nurse, a role recently introduced in the UK, is a further alternative [48,49]. Table 2 outlines the key characteristics of each of these roles, information that helps in decision-making. The undertaking of any of the roles outlined in Table 2 will enable nurses to take a lead and oversee the long-term follow-up of children/young people with cancer; evolution of the role being defined by the parameters of the specialist service and not constrained by role definitions. Thus, children/young people and their family will have access to a specialist care provider and this will increase the likelihood of continuing care. Developing the role of the nurse offers greater autonomy and the opportunity to extend the limits of the nursing profession [35].

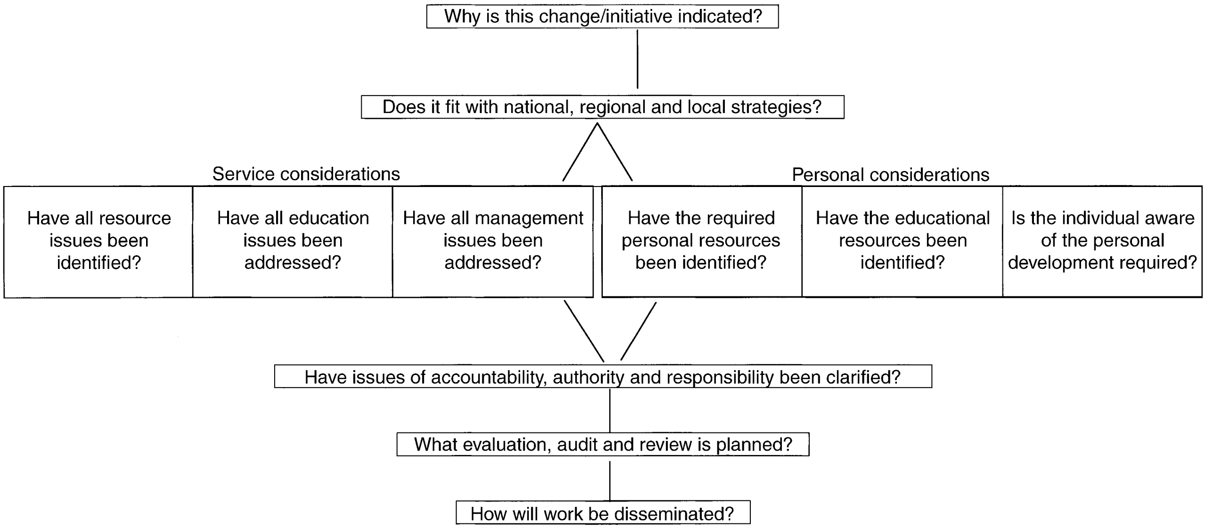
Whatever role is developed will need to be described by patient need and this is consistent with the recently published NHS Plan [50]. In order to develop a sound knowledge and focused clinical expertise, the role of the nurse in long-term follow-up must not continue to be filled by a nurse who 'has an interest in the subject'. Whatever developments take place, and they must, in order to provide appropriate care to the increasing number of survivors, a framework would be required to analyse, describe and evaluate role developments. One such framework has been applied to paediatric oncology nursing [51,52]. Its use has been suggested for nurses in clinical, management and education roles to use in collaboration with the multiprofessional team when considering any role development within their service (Fig. 2) [53]. This framework will enable nurses to act with confidence in devising and developing roles that are patient-centred and service-orientated, ultimately contributing towards the development of advanced paediatric oncology nursing roles [51,54,55].

7. A way forward

There is a continuing responsibility not only to care for survivors who have physical long-term effects, but also to ensure the general well-being of all cancer survivors. All survivors need a long-term relationship with a competent healthcare professional (nurse, physician, primary care provider, etc.) whom they trust [39]. Decisions need to be made about 'who', and 'how' in rela-

Table 2
Key characteristics of nurses in advanced practice roles (UK)

Role	Clinical nurse specialist	Nurse practitioner	Consultant nurse
Purpose	• Provide collaborative and direct patient care • Provide patient and staff education and practice development • Provide information and consultancy services • Use nursing diagnosis to plan care • Improve quality by direct care or through work with other nurse	• Provide direct primary and speciality care in a variety of settings • Provide full range of primary healthcare services with a holistic patient and family focus• • Use nursing and medical diagnosis to plan care	• Provide better outcomes for patients Improve services and quality • 50% clinical practice • Strengthen leadership • Provide a new career opportunity to retain experienced and expert nurses
Functions	• Expert practice • Education • Consultation • Research	• Health promotion • Physical assessment • History taking • Establish medical diagnosis • Order, perform and interpret results • Prescribe drugs • Refer patients • Provide emergency care	• Expert practice • Professional leader • Consultancy role • Education, training and development function • Practice and service development • Research and evaluation function
Qualifications and experience	• Educated to first or masters degree level • Specialist professional qualifications • Experienced and expert in a defined area of practice	• Educated to first or masters degree level • Undertaken a nurse practitioner type programme • Specialist professional qualifications • Experienced and expert in a defined area of practice	• Educated masters up to doctorate level • Considerable breadth and depth of clinical experience • Specialist professional qualifications considered appropriate for recognition of a 'higher level of practice'



Source: Coombs M and Holgate M (1198) Developing a framework for practice: a clinical perspective. Chapter in Rolfe G Fulbrook P. Advanced nursing practice. 1998 Butterworth Heinemann, Oxford.

Fig. 2. Safety net to support professional practice in paediatric oncology nursing (Source: Ref. [57]).

tion to follow-up. The status has to be modified, imaginatively, because the number of long-term survivors will continue to escalate. The survival statistics are, of course, good news for patients and their families and all concerned must be reassured that continuing care will remain an important feature throughout the follow-up of children/young people. Healthcare professionals must be prepared to continue to provide optimum care for children into their adult life. Alternative approaches must therefore be considered as well as the role of, purpose of and perceived patient benefit of follow-up. Any changes must aim to preserve and improve the care and therefore need to be carefully introduced and evaluated [32]. The time is right to:

1. Evaluate delivery of services and current arrangements for long-term follow-up.
2. Consider guidelines from the UKCCSG [23] and the International Society of Pediatric Oncology (SIOP) [36].
3. Consult the survivors, parents, children/young people.
4. Use the paediatric oncology nursing framework to develop/introduce new roles [52].
5. Take up the challenge and maximise the nursing contribution.

8. Conclusion

The aim of surveillance in the early follow-up of children is primarily early detection and treatment of recurrent disease. However, the emphasis changes for the long-term survivor where it becomes important to identify and anticipate late effects of therapy. In addition, the follow-up of children/young people long-term facilitates collection of data on the incidence, consequences and management of late effects, knowledge that is essential when developing new treatment regimens. Balanced against these aims, there must be benefits for children/young people and their families in terms of survival and quality of life [32].

The right education, training, research and clinical experience will ensure that the healthcare professional leading the long-term follow-up is a specialist in caring for childhood cancer survivors. This paper has made a case for that healthcare professional to be a nurse. We would welcome any correspondence and opinion on the issues raised by this paper (contact via e-mail gibsonf@sbu.ac.uk) and look forward to a lively debate with nurses and physicians involved in caring for children/young people with cancer.

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Commentary

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I provide this commentary from several different perspectives; I am a member of the Executive Committee of the International Confederation of Childhood Cancer Parent Organisation (ICCCPO) and also the parent of a long-term survivor. I am also a Chief Professional Nurse/Parent Consultant in a South African Paediatric Oncology Unit.

The follow-up clinic and work by Wendy Hobbie and the Rochester Hospital team in the USA presented in the 1995 at the 'Pieces of the Puzzle' conference of the American Candlelighters was inspiring.

For the past 21 years, I have been part of the multidisciplinary care team involved in Paediatric Haematology Clinics at Johannesburg Hospital. With 'an interest in survivors', I am seen as the 'mother figure' in the clinic as the young patients will often speak to me about the problems they are having, or ask questions they are afraid or too shy to put to the medical consultants. Many issues come up, such as:

- Reproduction, and if they can have a child will it too have a cancer?
- Vocational guidance, taking into consideration possible educational or physical deficits.
- Discrimination in the workplace, and also where life insurance is concerned.
- Is there a need to come back to the clinic?

Long-term survivors need consistent support in their goal to lead a normal and fulfilled life.

Long-term survivors are receiving greater attention at the ICCCPO and International Society of Pediatric Oncology (SIOP) conferences. Furthermore, I agree with Gibson and Soanes that there has to be a co-ordination of the follow-up of survivors, as well as a transitional care programme that takes the patient from paediatric care into adulthood. Nurse Co-ordinators could be the person in the multidisciplinary team to take on that responsible role, but I feel we should take a broader look at what is needed, rather than viewing it primarily from the perspective of just one discipline.

The starting point should be a set of clear statements defining the roles and functions that should be available to the long-term survivor. We would hope that a consensus can be developed as part of "standards of care" guidelines. The skills, expertise and personal attributes required to fulfil these roles could derive from a range of backgrounds, including nursing, medicine, social work, psychology, parents, as well as from the survivors themselves.

It is critical to recognise that follow-up of long-term survivors requires a multi-disciplinary approach, in the same way that treatment in the specialist units brings together all of the relevant disciplines, together with the parents. While nurses could indeed play a leading role, it is the personal attributes of the team members (and the leaders particularly) that are probably of greater importance than their formal academic qualifications. Each country (and even region or unit within a given country) has its own specific set of problems and constraints, and will have to set its priorities within the local context, as to what is possible. Similarly, each unit or country will need to assess the most appropriate combination of available people and attributes that can be utilised.

Most workers in Paediatric Oncology will be familiar with the various SIOP Guidelines formulated in recent years, especially for psychosocial support. ICCCPO is working on the development of 'Standards of Treatment and Care' for Childhood Cancer, which will hopefully be adopted and take their place alongside

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