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Review

A review of long-term follow-up for survivors of childhood cancer

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ABSTRACT

Though cure from cancer is not guaranteed, children's chances of survival have increased significantly. As a result the paediatric oncology community is focused on providing appropriate follow-up care to an increasing number of young cancer survivors. How this care should be designed and delivered however remains the centre of ongoing discussion and was the focus of this review. The aims of the review were to (1) gain an understanding of current follow-up practices from studies involving health care professionals, (2) identify and evaluate studies presenting views of survivors, (3) examine commentaries on both the current and future design of long-term follow-up services and (4) evaluate existing follow-up guidelines. Empirical research, commentary papers and published guidelines were reviewed. Twenty-eight papers and five guidelines were analysed. Empirical papers were examined in relation to sample, design, findings and limitations. Commentary papers were assessed in relation to key issues about follow-up care. Guidelines were assessed on how far they were evidence-based, peer-reviewed and involved users in their development. Varying models of care were illustrated, and were dependent upon personnel and centre orientation. Variability in the level and degree to which long-term survivors were followed up was also reported. Inconsistencies in practice were noted. Nonetheless requirements for an effective service were highlighted in the majority of publications, these included communication and information. Although young people and professionals had a shared view on many aspects of follow-up care, these preferences were not consistently mirrored in service provision.

1. Introduction

Throughout the world there are an increasing number of cancer survivors. Within the United Kingdom (UK), there are more than 26,000 survivors of childhood cancer compared to 1400 in 1971.[1] It is estimated that this number will increase by at least 1200 per annum.[2] Five year post-treatment survival rates now exceed 70% and 1 in 715 young people is a survivor

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of childhood cancer.[3] Yet despite these positive increases in survival rates, it is still estimated that approximately 60% of survivors will have one or more treatment or disease related late effects, with over 30% of these being classified as moderate or severe.[4–10] Moreover, as many as 30% of survivors will have significant psychosocial late effects.[11–13] Follow-up for life is recommended to improve detection in late effects and provide information and advice to those living with the consequences of cancer and its treatment.

The aim in the early follow-up period is prompt detection and treatment of recurrent disease. However, emphasis changes for the long-term survivor, here it becomes important to identify and anticipate late effects of therapy. Traditionally, this generally has a physical focus and follows a monitoring rather than health promoting model of care. Long-term follow-up of young people also facilitates collection of data on incidence, consequences and management of late effects: knowledge that is essential when developing new treatment regimens and influencing approaches to future care. Balanced against these aims, there must be benefits from follow-up for young people and their families in terms of influencing health-related quality of life and survival.[9]

For the past 30 years the predominant view has been that all survivors of childhood cancer should be followed up for life.[14] However, encouraging survival statistics has led to increased pressure on health care systems and resources and has prompted cancer care providers to ask whether life-time follow-up is feasible or in fact beneficial? Some researchers have questioned the efficiency of providing such a service to all survivors regardless of their treatment received and at present there is little evidence to support this belief.[15] This paper presents a review of the literature relating to long-term follow-up service provision for survivors of childhood cancer. The aims of this review were to (1) gain an understanding of the content of current follow-up practices from studies involving health care professionals, (2) identify and evaluate studies presenting views of survivors, (3) examine commentaries on both the current and future design of long-term follow-up services and (4) evaluate existing follow-up guidelines.

2. Methods

2.1. *Literature search strategy and study selection*

A review using systematic methods was carried out. A computerised search was undertaken using the following databases: Medline (Winspirs, PubMed, Gateway), Web of Science, Psychinfo, CancerLIT and BMJ Highwire. The search strategy used was (cancer) and (young person or young adult or adolescent or teenage* or adult) and (child* survivor) and (follow-up) and any of the terms such as long-term, health care, preferences, transition, and transfer. (*, truncation sign).

There were no date restrictions placed on the search with all databases being searched from their inception date until March 2006. Inclusion criteria were that childhood cancer survivors were diagnosed before 18 years of age, and were at least five years from diagnosis. Papers not published in the English language were excluded from the study as were papers examining follow-up services for adult cancer survivors and those that were related to medical late effects without recourse to long-term follow-up care. Experimental, descriptive, commentary and guideline papers were all included in the review.

2.2. *Data extraction*

Using a standard form to obtain information from each paper, they were classified into one of four groups:

- studies accessing childhood cancer survivors' views of follow-up;
- studies accessing health care professionals' views of follow-up of cancer survivors;
- commentary papers on follow-up provision and recommendations for future directions in service provision;
- guidelines and policy documents about long-term follow-up.

Data extracted depended upon whether it was an empirical study, commentary paper or guideline. For empirical studies the author(s), year, setting, aim, design, methods, findings and possible limitations were identified and tabulated. For commentary papers, the features identified were types of follow-up models and essential components of these (i.e. separation from acute clinics), information needs, barriers to follow-up, education of care providers and communication between health care providers. Finally, guidelines were assessed using a tool devised by Broughton and Rathbone[16] appraising the development process and the evidence base underpinning the recommendations.

3. Results

One hundred and seventy four papers were retrieved using the search parameters. Once the exclusion criteria were applied only 27 papers met the eligibility criteria. A further six studies and guidelines were identified through hand searching. This led to a total of thirty-three papers selected for this review. Five involved the views of adult survivors of childhood cancer, whilst three described health care professionals' views on follow-up and current service provision. Eighteen were commentary papers and seven were related to guidelines and policy.

3.1. *Empirical studies on childhood cancer survivors' views of follow-up*

Five studies were identified,[17–21] these varied in their design (Table 1). Three were questionnaire based[17–19] and the remaining two involved Delphi panel[20] and focus groups,[21] respectively. Of the questionnaire-based studies one was an audit obtaining survivors' satisfaction with current follow-up provision and preferences for future follow-up.[17] The second was used to assess the success of a booklet aimed at improving attitudes to follow-up and health awareness in survivors.[18] Both of these studies were undertaken in the UK. The final questionnaire study was a large-scale analysis of the level of contact of survivors with follow-up and health care services in the United States (US), and barriers to

Table 1 – Studies accessing the views of childhood cancer survivors

Study	Aim	Design and methods	Participants	Findings	Potential Limitations
Eiser et al.,[17] UK single centre study	To evaluate patient and parental understanding of reasons for attending clinic, satisfaction and future follow-up	Audit questionnaire given in clinic waiting area	Sixty-eight parents, 93 cancer survivors aged 11–26 years. Mean follow-up interval 11 years. Sixty-six percentage on annual follow-up, 23% seen every 6 months	Seventy percentage satisfied with current follow-up. Survivors (33%) reported persisting problems as a result of their illness. No difference in % of survivors who thought clinic was beneficial and those who did not. Parents more positive about their children attending clinic than the patients themselves	Questionnaire completed in clinic Non-attenders not approached No in-depth assessment of information needs or communication experiences No real information provided as to what cancer survivors would prefer from their follow-up clinics
Eiser et al.,[18] UK single centre study	Intervention study to improve attitudes to follow-up and health awareness in survivors	Questionnaire given on two occasions: at baseline and then following a clinic-based intervention (information booklet, information sheet, treatment summary)	Childhood cancer survivors (263) aged 16–32 years completed the initial questionnaire, of these 155 completed the second questionnaire	No change in ratings in the importance of follow-up between t_1 and t_2. However, patients felt that they had benefited from the information they had received, and between t_1 and t_2 there was a shift in behaviour change towards positive health behaviours	Non-attenders not approached Information was thought to be age appropriate, but not clear whether matched for intellect Inconsistency in the way in which the intervention was delivered by health care professionals – not everyone may have received the same level of information High drop out rate between t_1 and t_2
Oeffinger et al.,[19] USA Multi centre study	To determine follow-up patterns of survivors and potential barriers to follow-up	Postal questionnaire (retrospective cohort study)	Survivors (9434) aged 18–48 years <21 at diagnosis	Reduced visits to follow-up were related to the older age and longer follow-up. Ethnic minorities and males were likely to have less contact with follow-up services	Descriptive, did not assess survivors views on the actual follow-up care they receive Some of the participants could have been over the age of 16 or 18 when diagnosed
Zebrack et al.,[20] USA multi-centre study	To identify what survivors regard as barriers to follow-up care	Shortened Delphi Panel	Nineteen survivors involved in survivor groups and one parent. Age range 21–51 years. Median age at diagnosis 13.9 years	Survivors wanted ownership of their illness. They highlighted the lack of information and knowledge they had about their diagnoses and treatments. Follow-up in primary care was preferred, but survivors felt that staff in these settings were not qualified to provide the service and needed specific education in order to do so. Communication between primary and secondary care was also highlighted as a cause for concern	Sample bias. All of the survivors involved were experienced in advocacy for childhood cancer survivors Did not sample the views of non-attenders The diagnosis criterion for this study was diagnosis before the age of 30, but can someone of this age really be called a childhood cancer survivor?
Earle et al.,[21] UK single centre study	To assess the attitudes of young people and parents to current follow-up provision in the UK	Focus groups × 7 (parents and young people in the same groups)	Twenty-six, 13–25 year olds. Mean follow-up interval 12 years. Thirty-three parents	From their follow-up clinics survivors wanted more facts and information about their illness, health promotion and psychological support, although they played down late effects. Parents highlighted the need for parent support groups. In terms of service provision primary care follow-up was not favoured by survivors due to perceived knowledge deficits of staff. Specialist nurse led follow-up was regarded as acceptable as long as it was possible to access a doctor	Parents and survivors in the same focus groups, so may have affected views Very low response rate (8%) Non-attenders views not sampled

follow-up.[19] The Delphi panel technique was employed with survivors of childhood cancer in the US to examine perceived barriers to care in relation to information provision, education of professionals and financial demands.[20] The focus group study assessed what young people and parents' felt was needed from long-term follow-up with regard to alternative models of care and barriers and attitudes to care in the UK.[21]

Alternative models of care were addressed in four of these five studies.[17,19–21] In the Delphi study,[20] survivors rated follow-up by specialists in primary care as the preferred method of follow-up (see also [19]). Both of these studies used US samples; however, in the two UK studies in which this issue was addressed, hospital-based follow-up by specialists was preferred.[17,21] In the two latter studies, follow-up in a primary care setting was not seen as appropriate as general practitioners were perceived to lack specialist knowledge.

Barriers to follow-up care were considered in four of the five papers.[17,19–21] Follow-up care was described as losing relevance to survivors over time,[21] with increasing age and years since diagnosis attendance at follow-up appointments became less frequent.[19] Ethnicity and gender were also found to affect attendance rates,[19] as were factors such as travelling time to clinic and work demands.[17] Lack of psychosocial support was also regarded as a barrier to follow-up care.[21] Survivors regarded follow-up as an opportunity to learn more about their illness, treatment and late effects.[17,20,21] If there was lack of knowledge however about the reason for attending[17] or if young people did not receive the information they required, follow-up began to lose meaning.[17,20,21]

The need for quality information provision was highlighted in all five studies.[17–21] Survivors sought to be well informed about diagnosis, treatment and potential late effects[17,20] and risk levels.[19] They felt that a mismatch existed between what they would like to be told, and what they were actually told.[17] The importance of careful and appropriately timed dissemination of information was also highlighted.[21]

Survivors also commented on their perception of knowledge and educational levels of health care providers.[19–21] It was felt that primary care providers needed to receive greater training in the specific needs of this group. Furthermore, in two of these studies[19,20] survivors felt an increased need for communication between different care providers, particularly where care was to be transferred from secondary to primary care providers.

3.2. *Empirical studies on health care professionals' views of follow-up*

Three studies (see Table 2) were identified which involved health care professionals views on current follow-up for survivors of childhood cancer.[22–24] Two were descriptive postal questionnaires aimed at capturing the follow-up practices of clinicians in the UK[22] and the US, respectively.[23] Taylor and colleagues[22] examined long-term follow-up and discharge policies of cancer centres in the UK and Ireland, and compared this to the extent to which primary care providers believed their patients were receiving hospital-based long-term follow-up. Oeffinger and colleagues[23] assessed follow-up practices in the US, clinic organisation and barriers to follow-up. Provision was found to be patchy with less than half of survivors found to be followed up in adulthood. The third study involved US health policy experts identifying barriers to follow-up care using the Delphi panel method.[24] In the latter paper, idealised models of care and methods of enhancing health care provision were discussed.

All three of these studies discussed the future direction of long-term follow-up care. Greater nurse and primary care involvement and follow-up based upon risk were advocated.[22] Transition to adult care providers, surveillance and screening and an increase in psychosocial support were also highlighted.[23] The Delphi panel[24] proposed three models of follow-up: guideline based, multidisciplinary chronic disease prevention model; a transition to primary care model with back-up support from secondary care specialists; and a multidisciplinary late effects model focusing on screening and service-user education.

Barriers to follow-up service accessibility and provision were addressed in all three papers. Concerns were expressed that survivors were unaware of the importance of follow-up and the incidence of late effects[23,24] and that this leads to unwillingness to be followed up.[23] Increasing age of survivors was also observed to correspond with a decrease in accessing follow-up services.[22,23] Potential system barriers such as lost medical records and breakdown in communication between care providers were also identified.[23] Improving communication between primary and secondary care providers and child and adult services was a recurring theme in two of these papers[22,24] as was the importance of providing specialist education for nurses and primary care professionals.

3.3. *Commentaries on follow-up provision and directions for the service*

Eighteen commentary papers (see Table 3) reflecting aspects of follow-up service provision and alternative models of care were identified.[25–42] These papers varied in whether they related to existing service provision or made suggestions for future models of follow-up.

3.3.1. *Alternative models of follow-up*

Twelve papers explicitly described hypothetical and actual alternative models of follow-up care and best practice for survivors of childhood cancer.[25–36] These models fell into four groups: (1) transitional models of follow-up, (2) nurse-led/key-worker models, (3) stratified follow-up services and (4) psychosocial models of follow-up.

3.3.2. *Transitional models of long-term follow-up*

Transitional models, which stressed the importance of guided and well-planned transition between paediatric and adult oncology services and transfer to primary care, were specifically described in eight papers.[25–32] Three of these papers commented on services already in place,[25–27] whilst five made suggestions for future models.[28–32]

A model of prepared transition to a multidisciplinary team is already in place in Slovenia,[25] where upon reaching 16 years of age survivors are transferred to a multidisciplinary team in an adult hospital headed by an adult specialist known to the patient. The St. Jude Model (US) of transitional care

Table 2 – Studies accessing the views of health care professionals about follow-up

Study	Aim	Design and methods	Participants	Findings	Potential Limitations
Taylor et al.[22] UK mutli-centre study	To investigate the follow-up practices of clinicians in the UK	Two postal questionnaires 1. UKCCSG centres 2. Primary care providers Either use this or Gp and explain abbreviation	Clinicians in 17/22 UKCCSG centres = 71 GPs = unspecified number, but account for 10,979 survivors	Fifty-two percentage of clinicians' follow-up survivors for life. Forty-five percentage discharge some of their patients after 5 years to other services (GP = 97%). Sixteen percentage discharge all of their patients to a GP or adult oncologist. GPs survivors (65%) (7141 cases treated 1940–1991) not receiving regular hospital follow-up	Lack of response from five of the centres. Limited questions in order to maximise response
Oeffinger et al.[23] US	To establish follow-up patterns in the US and HCPs perceptions of potential barriers to follow-up	Postal questionnaire	*N* = 182 (does not say who completed the questionnaire)	Survivors (44%) are receiving follow-up. Of these 93% are followed up by paediatric oncologists. Respondents (8%) reported some primary care involvement in follow-up, 70% reported nurse involvement. Consultants available in clinic time at 57% of the respondents' centres. Only 44% provided survivors with information sheets and 34% centres had patient databases. Barriers to follow-up included patient uncertainty as to the need for follow-up (70%), inability to trace survivors (66%), survivors not seeking follow-up (66%)	Only descriptive information is provided no sense of the scale of particular problems highlighted Honesty of respondents in terms of the amount of follow-up provision provided
Mertens et al.[24] US	To identify barriers to follow-up, ideal models of care and improvements that could be made to follow-up	Delphi Panel of health policy experts	Seventeen experts including medical directors, cancer board representatives and others with experience in health policy. Fourteen participants took part in all three Delphi rounds	Experts identified primary care providers as being unfamiliar of specific problems and risks for survivors, and also survivors' ignorance of risks and lack of knowledge. Highlight need for education for both groups	Small sample questioned Study only generated hypotheses, did not provide any solutions

UKCCSG, United Kingdom Childhood Cancer Study Group.

Table 3 – Commentary papers on the topic of long-term follow-up

Study	Focus	Proposes alternative models of care	Transition services/ care	Nurse as key-worker	Stratified follow-up	Separation of follow-up clinics from treatment clinics	Barriers to follow-up	Information provision	Education of care providers	Communication between primary, secondary and tertiary care
Jereb[25] Slovenia	Slovenian model of follow-up	√	√	x	x	x	√	x	x	√
Hudson et al.[26] US	The St Jude's model of transitional care and nurse-led interventions	√	√	√	x	√	x	√	√	√
Ginsberg et al.[27] US	Lack of LTFU programmes	√	√	x	x	x	√	√	√	√
Viner[28] UK	Transition of survivors of cancer to age-appropriate services	√	√	x	√	√	x	√	√	√
Harvey et al.[29] US	The need for dedicated follow-up programmes	√	√	√	x	√	x	√	√	√
Goldsby and Ablin[30] US	How follow-up care should be organised	√	√	x	√	√	√	√	√	√
Bhatia and Meadows[31] US	Direction of LTFU care	√	√	x	x	√	x	x	√	√
Friedman et al.[32] US/UK	LTFU provision	√	√	√	√	√	x	√	√	√
Richardson[33] US	Needs of cancer survivors, barriers to follow-up and components of follow-up	√	√	x	x	x	√	√	√	x
Gibson and Soanes[34] UK	Role of nursing in follow-up care	x	√	√	x	x	x	x	√	x
Von der Weid and Wagner[35] Switzerland	Components of follow-up, young people's attitude to follow-up	x	√	x	√	√	√	√	√	x
Hobbie[36] US	The role of nurse specialists in follow-up	√	x	√	x	x	x	√	√	√
Hobbie and Hollen[37] US	The extension of nurse specialist role in follow-up	√	x	√	x	x	x	√	√	√
Wallace et al.[38] UK	Graded levels of follow-up care	√	x	√	√	x	x	x	x	x
Gibson[39] UK	Do all survivors require the same level of follow-up?	x	x	x	√	x	x	x	x	x
Oeffinger and Wallace[40] US/UK	Barriers to follow-up in UK and US	x	x	x	x	x	+	+	+	+
Phillips[41] US	Barriers to follow-up and importance of providing information to follow-up	x	x	x	x	√	√	√	x	x
Landier[42] US/UK	Need for education of health care providers	√	√	√	√	√	x	√	√	√

involves phased education and transition to primary care providers.[26] Transition to a specialist programme is also reported.[27] Here, young adults are seen in paediatrics until 22 years of age and then go through a 1–2 year transition programme before moving into the "Living Well After Cancer" programme.

Four papers proposed a transition-based model that combined both paediatric and adult specialities involved in all aspects of follow-up throughout the life course of each survivor[28,29,31,32] and three other papers also highlighted the importance of transition.[33–35] Goldsby and Ablin[30] support the design of programmes already in place ,[25–27] but also suggest a conditional discharge transition model in which the childhood cancer survivor is discharged from care with appropriate information concerning their condition, but has the facility to seek follow-up care when needed.

3.3.3. *Nurse-led models of care/nurse as key-worker*

Three papers provide commentaries on a nurse-led model of care that has been in place in the US since 1983.[29,36,37] Four further papers theorize a potential role for nurse specialists and how this might be progressed.[32–34,38]

3.3.4. *Stratified models of follow-up*

The suggestion that follow-up care should be tailored according to diagnosis, treatment received and perceived level of need was addressed by six papers.[28,30,32,35,38,39] The need for stratification of service provision was emphasised in terms of overstretched services and the need to provide care that is appropriate and economically viable.

3.3.5. *Psycho-social model of follow-up*

Two papers described models that incorporates specific psycho-social follow-up.[25,33] Richardson[33] presents a model in which young-adult survivors of childhood cancer can elect to participate in group sessions addressing issues affecting and challenging them such as self-identity, relationships and employment. Whilst Jereb,[25] using a multidisciplinary team, incorporate psychosocial support into routine follow-up.

3.3.6. *Separation of follow-up clinics from treatment clinics*

Six papers expressed the need for survivors to be seen in clinics separate to where children and/or adults were undergoing active treatment.[28–30,32,35,41] The reasons cited were anxiety and emotional distress associated with returning to their treatment clinics[30,32,35,41]; the stress of seeing other children or adults on active treatment[28,29]; and having appropriate time given to their needs and fears.[29,32]

3.3.7. *Barriers to follow-up*

Seven papers highlighted barriers to follow-up care. [25,27,30,32,35,40,41] Barriers described were survivors wanting to move away from their illness rather than being reminded of it[33,35,41]; inappropriate clinic settings[41]; lack of specialist clinics[33]; location of clinics far away from where patients lived[30]; not understanding their disease and the importance of long-term follow-up and the benefits of attending[30,33,40]; and clinicians not understanding the young person's needs.[28,40] Cross-cultural barriers to follow-up were similar in the UK and the US except for insurance provision being an added barrier in the US.[40] Ginsberg et al.[27] themed barriers into those which were patient driven, family-related, paediatrician driven and adult clinician related.

3.3.8. *Information provision*

The need for survivors of childhood cancer to be informed about their condition in relation to initial diagnosis, treatment and possible late effects was highlighted by 13 papers.[26–30,32,33,35,37,40,41] Concern was expressed in one paper about how little some survivors knew about their cancer.[42] The need for information concerning fertility, sexual relationships and psychosocial support was specifically highlighted.[33] Information was seen as a way of empowering patients.[26] Recommendations were made for educational leaflets to be made available to all patients.[29,36,37,41] More recent papers highlight the use of internet web-based provision of tailored resource material for survivors.[32,41]

3.3.9. *Education of care providers*

Fourteen papers stressed the importance of providers of follow-up care being suitably educated.[26–38,40,42] Adult health care providers were seen to lack specific knowledge related to childhood cancer,[28,29] whilst paediatricians were regarded as lacking in knowledge concerning the late effects of ageing, early menopause and adult-oriented problems.[27–29,31,40,42] One paper specifically expressed a need for all follow-up providers to be educated about survivors' psychosocial needs.[33] It was felt that primary care providers in particular should be supplied with specific follow-up guidelines.[30] Education of health care professionals was envisaged as a role that nurses specialising in follow-up could undertake in the community.[29,36,37]

3.3.10. *Communication between primary, secondary and tertiary care*

Eleven papers commented on the need for communication between primary, secondary and tertiary care in follow-up.[25–32,36,37,40] This was seen as implicit in the successful transition of follow-up provision.[25,26,28,30,31] The importance of having a service that is multidisciplinary in nature was highlighted[29,36,37,40] and the nurse specialist in a key-worker role was regarded as playing a vital part in the maintenance of communication pathways.[29,36,37]

3.4. *Guidelines and policy documents on long-term follow-up*

A total of five guideline and policy documents were identified[2,43–46] and two further papers[47,48] linked to the development of one of the policies[43] (see Table 4). Three of the guidelines included evidence-based recommendations and input from clinical experts.[2,43,44] One guideline underwent critical appraisal,[44] and one was based on working committee recommendations.[46] The guidelines were specifically designed to standardise care and to inform monitoring procedures to help in early diagnosis and intervention of complications of cancer treatment. The importance of continued monitoring of patients was highlighted by three of the guidelines.[2,43,44] Risk-based follow-up was key to four of the documents.[2,43–45] All of the guideline and policy documents

Table 4 – Guidelines

	Defined the subject [what does this mean]	Group development of guidelines [is this meaningful]	Consumer involvement	Evidence based	Recommendations provided	Peer review	External review/update [what is meant by external review]
National Institute for Health and Clinical Excellence[2]	Yes	Yes	Yes (Patient/Carer representative)	Yes	Yes	Yes	Yes
COG Guidelines[43]	Yes	Yes	Yes (Patient advocacy group)	Yes	Yes	Yes	Yes
Scottish Intercollegiate Guideline Network[44]	Yes	Yes	Yes (Patient representative)	Yes	Yes	Yes	Yes
United Kingdom Children's Cancer Study Group[45]	Yes	Yes	No	No	Yes	No	No
International Society of Paediatric Oncology[46]	Yes	Yes	No	No	No	No	No

expressed the need for patients to have written summaries of their diagnosis, treatment and possible late effects, in some reference to customised follow-up plans was advocated. The necessary skill mix to provide care was addressed by three of the documents with reference to the use of specifically trained nurses. The role of a key worker was highlighted by two of the documents.[2,44] Service users were involved in the development of three of the documents.[2,43,44]

4. Conclusion

The goal of this review was to gain an understanding of current and preferred follow-up practices for survivors of childhood cancer from both health care professionals and service user perspectives. The intention was to synthesise and present a summation of three forms of evidence related to follow-up care: empirical research, commentary papers and guidelines.

The review reveals inconsistencies in current service provision and highlights often fragmented and patchy provision[22,23] marked by poor information,[17–21] low follow-up rates,[22,23] lack of specialist education[17,19–21] and communication breakdown between service providers.[19,20,22,24] However, whilst these variations exist, it is important to acknowledge the close correspondence between what health care providers aspire to see from their service, and what survivors of childhood cancer articulated that they wanted. This propinquity was in relation to the need for relevant education for health care professionals,[17,19–21,24,26–37,40–42] improved communication between service providers[25–32,36,37,40] and meeting the informational needs of survivors.[17–21,26–30,32,33,35–37,40–42] The need for targeted, age- and comprehension matched information was also a shared theme. This is reflective of findings from previous studies where more than 10% of survivors of childhood cancer reported being unable to name their illness[49] and that levels of knowledge varied as a function of age at diagnosis, time since diagnosis, race and tumour type.[49,50]

In spite of the consistency between survivors and professionals preferences for follow-up care, these were rarely mirrored in the service provided. Up to a point paediatric focused services would seem to serve a purpose, offering age and developmentally appropriate care to children. There is evidence, however, of need for service development for the increasing number of young people surviving into adulthood, who continue to need support services to achieve their physical, social and psychological potential. The need is becoming more obvious and acute for a well-developed follow-up service where childhood cancer survivors are seamlessly and appropriately followed up in the adult arena by a suitable health care provider who coordinates long term care. Adequate financial provision would be required for such a service that would rely on healthcare providers distinguishing between surveillance and treatment; placing these two specific requirements of follow-up care into appropriate services and meeting associated costs.

Evidence in this review of new approaches to follow-up care[25–27,29,36,37] may offer a solution to shared concerns of both survivors and professionals as they reflected theoretical consistency shown in the commentary papers.[26–37] Stratification, transition and appropriate ongoing care by a relevant professional were constant properties of future follow-up models of care. Risk-based follow-up according to initial diagnosis, treatment received, perceived risk of late effects and medical need was favoured by professionals.[2,28,30,31,35,38,39,44,46] Multidisciplinary teams spanning the age range of survivors, with tailored transition plans was advocated.[25–32] A key-worker who co-ordinates the care pathway and transition process, maintaining active links between services and the survivor, was favoured in the literature, with the potential of a nurse described as fulfilling this role.[21,22,24,29,32,34,36–38] This communication link may improve attendance rates and service uptake.[17,19–21,25,30,32,35,40,41]

Whilst debate by health care professionals as personified in the commentary papers reviewed is valuable, it was concerning that very few studies retrieved had sought the views of young people and health care professionals (five and three papers, respectively). Further research is clearly needed which incorporates their views into future service design and debate about different approaches to achieve mutually successful follow-up. Despite the shared perspective of young people and health care professionals illuminated in this review, a commitment to access and listen to the views of young people must remain a priority if we are to deliver care based on real rather than perceived or presumed need. Involving young people in the design, provision and evaluation of services affecting them is a well-established policy.[51] Without determining the views and preferences of service users future service provision may never wholly fulfil its objectives and meet the needs of those it is supposed to be serving: it may not pay attention to the things that are most important to young people. It is of vital importance that research is undertaken into developing, piloting, implementing and evaluating outcomes from follow-up models of care, so that in the future, reviews and commentaries will be based on evidence.

Conflict of interest statement

There is no conflict of interest.

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