



Shared care by paediatric oncologists and family doctors for long-term follow-up of adult childhood cancer survivors: a pilot study

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Summary

Background Since 75% of children with cancer will become long-term survivors, late effects of treatment are an ever increasing issue for patients. Paediatric oncologists generally agree that cancer survivors should be followed up for the remainder of their lives, but they might not be the most suitable health-care providers to follow up survivors into late adulthood. We designed a 3-year study to assess whether shared-care by paediatric oncologists and family doctors in the long-term follow-up of survivors of childhood cancers is feasible, whether a shared-care model is compatible with collection of data needed for registration of late effects, and how a shared-care model is assessed by survivors and family doctors.

Methods In 2004 and 2005, adult survivors of childhood cancers were randomly chosen from eligible patients diagnosed with childhood cancer (excluding CNS tumours) or Langerhans-cell histiocytosis between January, 1968, and December, 1997, and recalled to the long-term follow-up (LTFU) clinic at the University Medical Centre Groningen, Groningen, Netherlands, where they underwent physical and clinical assessments by an on-site family doctor (visit 1). At this visit, assessments were done according to guidelines of the UK Children's Cancer Study Group Late Effects Group, and late effects were graded by use of Common Terminology Criteria for Adverse Events (version 3). Follow-up assessments were done 1 year later in 2005 and 2006 by local family doctors (visit 2), who were asked to return data to the LTFU clinic. At this visit, the local family doctors were asked to complete a three-item questionnaire and patients were asked to complete a seven-item questionnaire about their satisfaction with the shared-care model. At the next consultation, which was planned for the end of the study (visit 3), the on-site family doctor advised patients about future follow-up on the basis of their individual risk of late effects. Main endpoints were numbers of participants, satisfaction ratings, and proportions of local family doctors who returned data that they obtained at visit 2 to the LTFU clinic.

Findings 133 individuals were chosen at random from 210 enrolled adult survivors. 123 of 133 (92%) randomly selected survivors and 115 of 117 (98%) of their family doctors agreed to participate in the share-care programme. 103 of 115 (90%) family doctors returned data to the LTFU clinic at visit 2. 89 of 101 (88%) of survivors were satisfied with this shared-care model, as were 94 of 115 (82%) family doctors; 18 of 115 (16%) family doctors had no views either way; and three of 115 (3%) family doctors were dissatisfied.

Interpretation Shared-care by paediatric oncologists and family doctors is feasible for long-term follow-up of adult survivors of childhood cancers.

Introduction

Most children with cancer will become long-term survivors and many of them will be at risk of treatment-related adverse health outcomes. Estimations suggest that physical or psychosocial complications will develop in as many as two-thirds of these survivors. The severity of these complications vary from mild to severe, and might even be life-threatening.^{1,2} 10% of survivors will die within 20 years of the end of treatment, some because of recurrence of primary disease, and others because of complications of previous treatment.³ To enable survivors to enjoy the best quantity and quality of life, identification and treatment of late effects as early as possible is important.⁴

For a long time, the discharging of paediatric patients with cancer after a disease-free interval of around 10 years was common practice. Nowadays, paediatric oncologists

world-wide believe that a systematic plan for life-long screening and surveillance should be offered to all survivors.^{5,6} Much effort is being invested in the development of guidelines for assessment of late effects of cancer treatment, such as the guidelines of the US Children's Oncology Group, the UK Children's Cancer and Leukaemia Group (CCLG), and the Scottish Intercollegiate Guidelines Network (SIGN). Up to now, many adult survivors are not being followed up on a regular basis.⁷ Of those who participate in follow-up programmes of childhood cancer, more than 90% are followed up by a paediatric oncologist in a paediatric institution.⁸ However, paediatric oncologists are not the most appropriate health-care workers to care for survivors into late adulthood. Patients who have been treated for cancer might have ongoing complex health needs and many comorbidities that need a range of approaches

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See **Reflection and Reaction**
page 191

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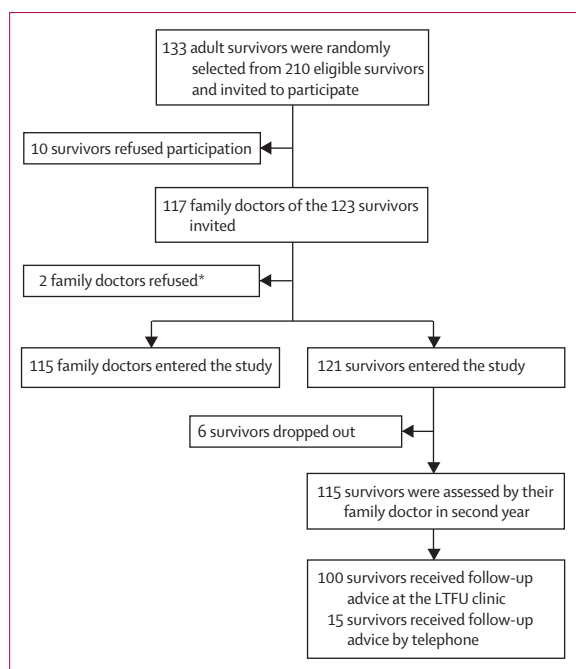


Figure: Trial profile

provided through general practice. In the Netherlands, survivors usually have family doctors, most of whom are willing to participate in a shared-care programme.⁹ In a shared-care programme, family doctors participate in the screening of late effects in adult survivors of childhood cancers in consultation with paediatric oncologists of the LTFU clinic.

Since the number of survivors of childhood cancers is expected to increase, identifying who should undertake long-term follow-up of such patients after achieving adulthood is important. Hospital-based life-long follow-up for all adult survivors will not only be very expensive, but also difficult to organise because of the ever-increasing population. From an economic point of view, we have to look for alternative follow-up programmes with the lowest burden, not only for survivors, but also for the expanding health-care budgets in many western countries. Family doctors will treat increasingly more of these patients, with a mean of eight or nine patients who survived childhood cancers registered with every family doctor predicted by 2010 (on the basis of a mean of 2350 patients registered for every family doctor).¹⁰ If guidelines and ongoing supervision were made available from clinics such as the long-term follow-up (LTFU) at the University Medical Centre Groningen (Groningen, Netherlands), the assessment of late effects could be undertaken by family doctors. If serious late effects, such as cardiac or endocrine complications were detected, survivors could be referred to an appropriate consultant. Involvement of family doctors in shared-care programmes for long-term follow-up would increase their knowledge about the unique needs of survivors of childhood cancers.

To assess shared-care by family doctors and paediatric oncologists in long-term follow-up of survivors of childhood cancers, we designed a 3-year study to assess whether such a model is feasible, whether shared-care is compatible with collection of data needed for registration of late effects, and how a shared-care model can be assessed by survivors and family doctors.

Methods

Patients

210 adult (ie, aged 18 years or over) survivors were enrolled into the study. Patients were randomly chosen by use of a computer program and recalled to the LTFU clinic in the first year of the study and were eligible if they had been treated at the paediatric oncology department of the University Medical Centre Groningen (Groningen, Netherlands) at least 5 years previously and were not involved in any childhood cancer follow-up programmes. Patients who were diagnosed with childhood cancer or systemic multifocal Langerhans-cell histiocytosis (LCH) between January, 1968, and December, 1997, were included. Patients with tumours of the central nervous system were excluded because most of them were being followed up by a multidisciplinary neuro-oncology team.

Procedures

In 2004 and 2005, survivors were recalled to the LTFU clinic at the University Medical Centre Groningen (Groningen, Netherlands; visit 1). An on-site family doctor with a special interest in late effects and who was employed by the LTFU clinic assessed the patients. Since Dutch guidelines were still under development at the time, the on-site family doctor used guidelines of the UK Children's Cancer Study Group (UKCCSG) Late Effects Group¹¹ to assess the survivors. Previous diagnosis and treatment established patients' risk-based assessments—eg, hormonal assessments, echocardiography, bone-mineral-density tests, or pulmonary-function tests. Late effects were graded by use of Common Terminology Criteria for Adverse Events (CTCAE; version 3).¹² CTCAE grades adverse effects from 0 to 4. Grade 1 effects are small and usually asymptomatic. Grade 2 effects are moderate, usually symptomatic, but do not impair daily activities. Grade 3 effects are severe and need more serious interventions. Grade 4 effects are potentially life-threatening. Health-related quality of life (HRQoL) at visit 1 (and also later at visit 3) was assessed by the RAND 36-item health survey (RAND-36). RAND-36 is an internationally used validated, reliable, generic self-report questionnaire that has been translated into Dutch¹³ and validated for the Dutch population.¹⁴ RAND-36 contains eight subscales: physical functioning, social functioning, role limitations due to physical difficulties, role limitations due to emotional difficulties, mental health, vitality, bodily pain, and general-health perceptions. For each subscale,

	Participants (n=121)	Non-participants (n=12)
Median age at study, years (range)	34 (19–60)	28 (19–49)
Median age at diagnosis, years (range)	6 (0–38)	4 (1–18)
Median time since diagnosis, years (range)	27 (9–38)	25 (18–31)
Sex (n)		
Men	64	7
Women	57	5
Initial diagnosis (n)		
Leukaemia	53	3
Malignant lymphoma	20	1
Bone sarcoma	23	3
Soft-tissue sarcoma	6	1
Wilms' tumour	4	0
Langerhans-cell histiocytosis	8	2
Other	7	2
Treatment (n)		
Chemotherapy only	48	9
Radiotherapy only	5	0

Table 1: Demographic and clinical data of participating adult survivors and non-participants

	Study group (n=121)	Control group (n=416)	p
Physical functioning	84.9 (20.0)	89.7 (16.3)	p=0.011
Social functioning	85.4 (18.9)	89.4 (17.0)	p=0.027
Role limitations due to physical problems	80.7 (31.8)	82.7 (32.2)	p=0.0500
Role limitations due to emotional problems	86.6 (30.3)	84.6 (31.5)	p=0.472
Mental health	77.6 (16.1)	77.9 (17.7)	p=0.853
Vitality	62.9 (20.1)	68.2 (18.9)	p=0.005
Bodily pain	83.5 (19.2)	84.0 (22.9)	p=0.787
General health perceptions	67.4 (21.7)	75.9 (20.2)	p<0.0001

Table 2: Means and SDs for RAND-36 subscales, in survivors and in Dutch controls (aged 25–44 years) at visit 1

scores were coded, summed, and transformed to a scale from 0 (worst health) to 100 (best health). The control group for the HRQoL analyses consisted of 1036 people aged 18 years and over who took part in a previous health screening of the population of Emmen in The Netherlands.¹⁵ From the control group, mean scores of the subgroup aged 25–44 years (n=416) were used as reference values in our study. RAND-36 has been used in other studies to assess HRQoL in survivors of childhood cancers.^{16,17}

Follow-up of the assessed survivors was 1 year after their first visit, in 2005 or 2006 (visit 2), and was undertaken by local family doctors who had been sent information (from the on-site coordinating family doctor at the LTFU clinic) about patients' histories, health risks, and necessary tests. Survivors were sent letters asking them to make appointments of at least half an hour with their family doctors. The letters were accompanied by forms that were to be completed by the family doctors during the physical assessments at visit 2 (there were two forms: one for medical history and one for physical assessment). To maintain a complete survivor database

in our hospital, family doctors were asked to return these forms and the results of their tests. We assessed this shared-care model with a three-item questionnaire for family doctors that asked whether the information they had received from the LTFU clinic was sufficient to do the screening, whether they were satisfied with the collaboration, and whether they had any suggestions to improve the collaboration; survivors were also asked to complete a seven-item questionnaire about their views on their follow-up by use of a five-point Likert scale for their answers, ranging from very satisfied to very dissatisfied.

At the next consultation, which was planned 1 year after visit 2, in 2006 or 2007 (visit 3) and was done by the on-site family doctor at the LTFU clinic, survivors were advised about future follow-up on the basis of their individual risk of late effects. Survivors were divided into three groups as described by Wallace and colleagues.¹⁸ First, those with very low risk of future effects were to be followed up by a yearly health questionnaire by post that would be assessed by staff at the LTFU clinic. Second, survivors with moderate risk of late effects (ie, those who received chemotherapy or low-dose radiation) were to be assessed yearly by local family doctors, and fast and direct methods of communication (ie, email or telephone) to one member of staff at the LTFU clinic were suggested. Third, survivors with high risk of severe late effects—including those who had received moderate-to-high doses of radiotherapy, underwent bone-marrow transplantation, or received mega therapy (ie, intensive high-dose treatment)—were to be followed up in a shared-care model as described earlier in this report. Many of these high-risk survivors would also need care by specialists, such as endocrinologists, cardiologists, and orthopaedic surgeons.

To justify the conclusion that this model is feasible for the long-term follow-up of adult survivors of childhood cancers, proportions of participants (ie, survivors and family doctors), satisfaction, and numbers of those who returned data should be high—as close to 100% as possible. The study did not need ethics or approval from an institutional review board or patients' written consent.

Statistical analysis

Data were analysed by descriptive techniques that used frequencies, percentages, means, and medians as appropriate. One-sample *t* test was used to compare the mean RAND-36 scores of the study group with the mean scores of the Dutch norm (reference) group. Paired-sample test was used to compare the mean RAND-36 scores at the start (visit 1) and at the end (visit 3) of the study. Since the total study sample was small, differences between cancer types were not analysed. A significance level of $\alpha=0.05$ was applied in all analyses. Analyses were done with SPSS for Windows (version 14.0).

Role of the funding source

The sponsor of the study had no role in the study design, data collection, data analysis, interpretation, or writing of the report. WT had access to the raw data. RB had full access to all the data and had final responsibility for the decision to submit for publication.

Results

Of 210 enrolled adult survivors, 133 individuals were chosen at random and recalled by letter to the LTFU clinic in the first year of the study (visit 1; figure). The participants included eight bone-tumour survivors (osteosarcoma or Ewing sarcoma) who were older than 18 years at diagnosis and who had been treated when chemotherapy for osteogenic sarcoma was given by paediatric oncologists. Ten out of the 133 (8%) invited survivors refused for the following reasons: one patient was severely mentally retarded; two patients had an anxiety disorder and were afraid to return to the hospital; and the other seven patients felt well but did not wish to look back at their cancer experience. Therefore, 123 (92%) survivors agreed to take part in this study. Six of these survivors agreed to participate in follow-up, but were not prepared to attend the clinic visits and requested that all assessments were done by local family doctors. Although these six individuals had all three visits at their local practice, they were included in this study. 115 of 117 (98%) of the approached local family doctors (some had more than one patient) were willing to collaborate in the shared-care model, and two (2%) doctors refused (the two patients of these two doctors were invited separately by the LTFU clinic, but did not enter this study). In total, 12 of 133 invited survivors did not participate in the study, therefore, 121 survivors entered this study. Table 1 shows characteristics of all 133 individuals. Survivors completed HRQoL assessments by use of RAND-36 subscales. Table 2 shows the outcomes of the RAND-36 subscales for the study group, and the mean scores from the available Dutch reference group. Survivors showed significantly lower HRQoL scores compared with the control group on the subscales for physical functioning ($p=0.011$), social functioning ($p=0.027$), vitality ($p=0.005$), and general-health perceptions ($p<0.0001$).

At visit 2, 115 of 121 (95%) survivors were assessed by local family doctors. Of the six survivors who were not assessed, two survivors had left the country, two survivors were starting treatment with growth-hormones and therefore did not have time to visit their local family doctor, and two survivors decided to end follow-up because they did not want to be reminded of their cancer (figure). Completed forms for medical history and physical assessment were returned by 103 of 115 (90%) local family doctors, and two (2%) local family doctors reported findings of their assessments by telephone because their patients had forgotten to take the forms with them to visit 2. Complete data, including those for laboratory tests, radiographs, and echocardiograms were

	Patients, n (%)
Satisfied with care given by doctor	
Very satisfied or satisfied	89 (88)
Neutral	6 (6)
Not satisfied	5 (5)
Satisfied with time available during screening by doctor	
Very satisfied or satisfied	88 (87)
Neutral	3 (3)
Not satisfied	8 (8)
Satisfied with doctor's knowledge of my medical history	
Very satisfied or satisfied	78 (77)
Neutral	8 (8)
Not satisfied	14 (14)
Doctor's attitude was friendly	
Very friendly or friendly	94 (93)
Neutral	2 (2)
Not friendly	3 (3)
Satisfied with answers given by doctor	
Very satisfied or satisfied	85 (84)
Neutral	7 (7)
Not satisfied	8 (8)
Satisfied with booklet, summary of diagnosis, and treatment I received (n=121*)	
Very satisfied or satisfied	106 (88)
Neutral	13 (11)
Not satisfied	2 (2)
Before being recalled to follow-up, I was already informed about possible late toxic effects (n=121*)	
Yes	36 (30)
No	85 (70)

Data are for 101 of 115 (88%) patients who completed satisfaction questionnaires. *All 121 patients who entered the study were able to answer this question. Percentages might not add to 100% due to rounding.

Table 3: Patient satisfaction with shared-care follow-up according to Likert scale

received by the LTFU clinic from 98 of 115 (85%) local family doctors.

The seven-item satisfaction questionnaire was completed by 101 of 115 (88%) survivors (table 3). 89 of these 101 (88%) survivors were satisfied with the care given by the local family doctors at visit 2. 14 of the 101 (14%) survivors thought that their local family doctor's knowledge of their medical history was inadequate. The most frequent remarks for these patients were: "I had the feeling that the family doctor did not know what he/she was expected to do" (seven of 101 [7%] survivors), "there was too little time to perform the investigations" (five of 101 [5%] survivors), and, "I had the feeling the family doctor was reluctant to perform the investigation" (three of 101 [3%] survivors).

Data from the three-item questionnaire for local family doctors showed that 94 of the 115 (82%) participating local family doctors were satisfied with this shared-care collaboration and thought the information they had received from the LTFU clinic was adequate, 18 of 115 (16%) local family doctors had no opinion, and three of 115 (3%) local family doctors were dissatisfied.

Before visit 1, 85 of the 121 (70%) survivors had not received information about the possibility of late effects. At visit 1, 64 of 121 (53%) survivors had mild late effects (grade 1 or 2) and 48 of 121 (40%) survivors had moderate-to-severe late effects (grade 3 or 4); additionally 85 of 121 (70%) survivors had two or more late effects and 37 of 121 (31%) survivors were diagnosed with previously unknown grade 2–4 late effects that needed treatment or closer monitoring. The most commonly recorded late effects were cosmetic, eg, amputations, scars from surgery, asymmetric body growth due to radiation damage (35 of 121 [29%]), orthopaedic (24 of 121 [20%]), endocrine deficiencies (20 of 121 [17%]), infertility (19 of 121 [16%]), cardiac damage (11 of 121 [9%]), and second malignant tumour (11 of 121 [9%]). Five survivors had a second malignant tumour (one meningioma, one oesophageal carcinoma, and three basocellular carcinomas) that had not been diagnosed before.

At visit 3, 100 patients received advice at the LTFU clinic and 15 patients received advice by telephone. RAND-36 was completed by 110 of 115 (96%) survivors (data not shown). No significant differences in any of the subscales were noted between visit 1 and visit 3. More detailed information about late effects and HRQoL of almost the same study group has been published in an earlier study in which 117 of 121 (97%) survivors of our current study.¹⁹

Discussion

123 of 133 (92%) invited survivors and 115 of 117 (98%) family doctors agreed to take part in the shared-care programme. Since 89 of 101 (88%) survivors who completed satisfaction questionnaires and 94 of 115 (82%) family doctors were satisfied with the programme, our findings have shown that shared-care by paediatric oncologists and family doctors is feasible for long-term follow-up of adult survivors of childhood cancers.

Collection of long-term follow-up data for registration purposes of late effects is acceptable. However, improvement of the exchange of information between family doctors and the LTFU clinic remains a challenge. Shared electronic health records, including information about diagnosis, treatment, and future screening practices, might be helpful.²⁰ In our earlier study,⁹ 110 of 233 (47%) family doctors preferred communication by email or by use of a website to submit forms. In the same study, most family doctors were willing to participate in long-term follow-up of adult survivors of childhood cancers, on the condition that guidelines and adequate medical information were provided and that there was one contact person at the LTFU clinic. The family doctors in that study were a different group to that in the present study; although, there was an overlap of 13 family doctors between both studies. Models of shared care have been developed for chronic diseases such as diabetes, hypertension, and asthma,^{21,22} and there are some examples of shared oncological care for adult patients with cancer.^{23,24} Some studies suggest that

family doctors are willing to take part in follow-up care of patients with cancer,^{9,25} and that hospital follow-up provides no advantages compared with long-term follow-up in primary-care settings.^{22,24} “Developing personal relationships”, “gaining mutual respect”, and “increasing medical knowledge for the benefit of their patients”, seemed to be the most important motivational factors to persuade family doctors to collaborate with specialist services.²⁶ For shared-care models to be successful, family doctors need to view such programmes as an improvement from usual care in general practice, rather than as a downgrade from hospital practice.²⁷

In our current study, most (85 of 121 [70%]) of the survivors who were recalled had not received information about the possibility of late effects from treatment before their visit, and consequently, were at risk of delayed medical care if health problems were to occur. Therefore, survivors should be fully informed and family doctors should know about the possible late effects of cancer treatment and their effects on health; participation in a shared-care programme should help update family doctors' knowledge. In our study, all family doctors were given information on their patients' history, health risks, and required tests. But 14 of 101 (14%) survivors were dissatisfied with their family doctors' knowledge about their medical history. Improvement of family doctors' knowledge about late effects is important because this is important for survivors of childhood cancers.²⁸ Training in survivorship care should be incorporated into training programmes for family doctors.

At present, not all long-term survivors are in long-term follow-up, and as age increases, the likelihood of receiving adequate long-term follow-up decreases.⁷ Furthermore, whereas the incidence of many modifiable late effects of treatment increases with age, the likelihood of receiving cancer-related care decreases with time. Many cancer survivors are discharged years before follow-up, and some services still discharge survivors as soon as they reach adulthood.

Survivors sometimes view hospital-based follow-up as problematic as they reach adulthood. Loss of long-term cancer survivors to follow-up should be avoided because many of the potentially serious late effects might not manifest until decades after completion of treatment. Oeffinger and co-workers²⁹ reported that patients diagnosed with malignancy between 1970 and 1986 and who had subsequently survived cancer, showed increased vulnerability to diseases associated with ageing, such as second cancers, cardiovascular disease, renal disease, musculoskeletal disorders, osteoporosis, and infertility, compared with their siblings.²⁹ Therefore, adult survivors of childhood cancers should be recalled for follow-up.

In our study, a substantial proportion (48 of 121 [40%]) of adult survivors had moderate-to-severe late effects. In another study,¹⁹ such survivors had significantly lower quality of life compared with survivors who had no or only mild late effects. In the current study,

37 of 121 (31%) survivors had previously undetected late effects that needed treatment or closer monitoring. Therefore, the recall of these survivors was worthwhile for managing the late effects and for minimising morbidity and the risk of severe complications. The long-term costs of early identification and treatment of late effects need further study. Although we did not undertake a cost analysis, shared care probably costs less than follow-up in an LTFU clinic alone. As the number of cancer survivors is increasing, the time has come to identify new models of cost-effective long-term follow-up.

Up to now, long-term follow-up of childhood-cancer survivors has been mainly organised by paediatric oncologists, and family doctors have rarely been involved. Yet, paediatric oncologists are ill-equipped to assess adult patients. Highlighting the need for new approaches to long-term care, Goldsby and colleagues³⁰ suggested four possible models—those driven by patients, family doctors, paediatric oncologists, or adult medicine health-care workers. Each model has its advantages and disadvantages, and more than one model might be needed.³¹ Since childhood-cancer survivors are a very heterogeneous group, Wallace and co-workers¹⁸ suggested that follow-up should be organised into three levels according to a patient's individual risk profile.

Clear advantages of follow-up care given by local family doctors rather than by hospital staff include less patient travel, shorter waiting times, better patient familiarity with surroundings (ie, the doctor's practice), and less stigmatisation. As survivors grow older and possibly develop additional chronic illnesses of age, access to care in the context of total health needs is more useful.

In the past 10 years, studies have begun to document late effects of treatment in survivors of adult cancers.^{32–34} Care for these survivors, provided by oncologists, generally does not extend beyond surveillance for recurrence of the cancer, and after about 5–10 years, patients are discharged without specific plans for monitoring.

Busy oncology practices, which focus on patients undergoing active treatment, are not appropriate for life-long follow-up of cancer survivors. Collaboration with family doctors in a shared-care model might provide a solution. A few studies^{23,24} have suggested that such a model is applicable to the care of adult cancer survivors. Given predictions that 300 million people will be diagnosed with cancer over the next 15 years, and over one-third of these will become cancer survivors,³⁵ collaborative shared care between specialists and family doctors is needed.

Our study has some limitations. We did not use predefined criteria to establish whether our model would be successful enough to progress to the next phase of a large study. However, we think there is no standard of what would be an acceptable amount of participation, satisfaction, or return of requested data.

Since we only recalled survivors who were not receiving any kind of follow-up, we could not compare our model to others. More studies are needed to assess whether a shared-care approach results in an equitable standard of care for survivors. Family doctors already have the skills to screen patients at increased risk of developing health problems such as diabetes and cardiovascular disease. With easy ways to communicate with LTFU clinics and the availability of guidelines, they should also be able to screen adult survivors of childhood cancer. We wish to emphasise that the success of a shared-care model depends on a key coordinator, who could be an academic family doctor with an interest in late effects (as used in this study), a nurse practitioner, or a dedicated nurse.

Contributors

BMDJ, WAK, and AP participated in the conception and design of the study, and critical revision of the report. WT participated in the data collection, data analysis, and drafting of the report. WT, BMDJ, WAK, and AP approved the final report.

Conflicts of interest

The authors declared no conflicts of interest.

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