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ORIGINAL ARTICLE

Long-term follow-up of childhood cancer survivors in the Murcia Region: Preferences and attitudes of Primary Care professionals☆

A. Cárceles-Álvarez[a], J.A. Ortega-García[a,*], J.L. Fuster-Soler[b], G.A. Rivera-Pagán[a], M. Bermúdez-Cortés[b], V. Gomariz-Peñalver[a], E. Monzó-Nuñez[c], F.A. López-Hernández[d]

[a] *Unidad de Salud Medioambiental Pediátrica, Servicio de Pediatría, Laboratorio de Entorno y Salud Humana, Instituto de Investigación Biosanitaria de la Región de Murcia (IMIB), Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, Spain*
[b] *Sección de Oncología y Hematología Pediátricas, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, Spain*
[c] *Servicio de Docencia y Formación, Gerencia de Área n.° 1 Murcia-Oeste, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, Spain*
[d] *Departamento de Métodos Cuantitativos e Informáticos, Universidad Politécnica de Cartagena, Murcia, Spain*

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Abstract
Objective: To assess attitudes, beliefs and knowledge of primary medical care professionals as regards the follow-up of Childhood Cancer Survivors (CCS) and the introduction of a Long-Term Follow-Up Program for Childhood Cancer Survivors in the Region of Murcia (PLASESCAP-MUR).
Material and methods: Descriptive cross-sectional study using a structured, self-administered questionnaire. These questionnaires were sent to all primary medical care professionals in Murcia Health District 1.
Results: Response rate of 58% (100/172), with 71% and 22% being family physicians and paediatricians, respectively, of whom 49% provided medical care to a CCS in the last 5 years, with 84% reporting that they never or rarely received a detailed report of overall assessment of the survivor. More than 75% found that access to detailed follow-up information was quite or very useful; 95% prefer to consult experts when providing medical care to survivors, and 80% believe that improving the quality of the environment may decrease the morbidity and mortality of the survivors. A statistically significant relationship was found between the length of practicing medicine and the perception of the importance of environmental factors.
Conclusions: It seems to be important to increase the training of primary care professionals for the long-term follow-up of CCS, as well as having the detailed information through a

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* Corresponding author.
E-mail address: ortega@pehsu.org (J.A. Ortega-García).

personalised long-term follow-up of each survivor. PLASESCAP-MUR offers an integrated follow-up to CCS in a model of shared care between Long Term Monitoring Units and Primary Care Units.

PALABRAS CLAVE
Neoplasias;
Pediatría;
Supervivientes;
Seguimiento a largo plazo;
Atención primaria;
Salud medioambiental

Programa de largo seguimiento de supervivientes de cáncer pediátrico en la Región de Murcia: preferencias y actitudes de los profesionales de Atención Primaria

Resumen
Objetivo: Evaluar actitudes, creencias y conocimientos de los profesionales médicos de Atención Primaria acerca del seguimiento de los supervivientes de cáncer pediátrico (SCP) y divulgar el Programa de Largo Seguimiento de Supervivientes de Cáncer Pediátrico en la Región de Murcia (PLASESCAP-MUR).
Material y métodos: Estudio transversal descriptivo mediante cuestionario estructurado y autocumplimentado. Se enviaron cuestionarios a todos los profesionales médicos de Atención Primaria del Área de Salud 1 del Servicio Murciano de Salud.
Resultados: Tasa de respuesta del 58% (100/172). El 71 y el 22% eran médicos de familia y pediatras, respectivamente. El 49% atendió algún SCP en los últimos 5 años. El 84% refiere que nunca o pocas veces recibió un informe detallado de evaluación global del superviviente. Más del 75% encuentran bastante o muy útiles el acceso a información detallada de largo seguimiento. El 95% prefiere atender a los supervivientes conjuntamente con consulta de largo seguimiento. Un 80% considera que mejorando la calidad ambiental del entorno podría disminuir la morbimortalidad de los supervivientes. Se encontró una relación estadísticamente significativa entre años practicando medicina y percepción de importancia de algunos factores medioambientales.
Conclusiones: Para el largo seguimiento de los SCP parece importante aumentar la capacitación de los profesionales sanitarios de Atención Primaria y la información detallada a través de un plan personalizado de largo seguimiento de cada superviviente. PLASESCAP-MUR proporciona un seguimiento integrativo a los supervivientes de cáncer pediátrico en un modelo de atención compartida entre la Unidad de Largo Seguimiento y Atención Primaria.

Introduction

Any child with cancer is a childhood cancer survivor (CCS) from the time of diagnosis, and will continue to be one for the rest of his or her life.[1] In Spain, approximately 950 children less than 15 years of age are diagnosed with cancer each year.[2] In recent decades, their survival rate has increased spectacularly thanks to the progressive improvement in the available treatments, the creation of referral units in hospitals and international cooperation studies.[3] The overall five-year survival rate for childhood cancer in the autonomous community of the Region of Murcia is approximately 80%, very similar to the rates for the whole of Spain (77% in the 2000–2003 period) and Western Europe (81% from 1995 to 2003).[4,5] This increase in survival has brought forth the need to monitor for possible late relapses and the risk to develop subsequent neoplasms,[6–8] chronic diseases and dysfunctions that affect quality of life at earlier ages than the general population.[4,9,10] By the second decade of life, more than 60% of CCSs will suffer from at least one chronic disease related to the treatment they have received and/or associated environmental risk factors.[11] This trend continues to rise during the life of the survivor, and by around 50 years of age more than 50% of CCSs will have experienced a severe or disabling life-threatening or fatal disease.[12] National and international agencies recommend a structured and if possible lifelong follow-up of CCSs.[4,13–15] Different models to guarantee the adequate follow-up of survivors are being considered. In the Region of Murcia, which has an established public primary care (PC) health system, we have developed a shared-care model for the transition from hospital care (long-term follow-up unit) to primary care (PC) that is tailored to the specific needs of each CCS. Most adult and some adolescent CCSs are followed-up by their primary care physicians (PCPs),[15–17] and an appropriate transition from hospital to primary care is essential to guarantee the adequate long-term follow-up of CCSs. In Spain, the transition to PC is still performed in a mostly unstructured manner.[18] The aims of this study were to: (a) assess the beliefs, attitudes and preferences of PC physicians regarding the follow-up of CCSs, and (b) explain the basic structure of the Childhood Cancer Survivor Long-Term Follow-up Programme of the Region of Murcia (Programa de Largo Seguimiento de Supervivientes de Cáncer Pediátrico en la Región de Murcia [PLASESCAP-MUR]).