

Health care timeline for patients with retinoblastoma seen in Southern Philippines Medical Center: policy notes

Christine May Perandos-Astudillo,¹ Rodel C Roño¹

¹Research Utilization and Publication Unit, Southern Philippines Medical Center, JP Laurel Ave, Davao City, Philippines

Correspondence

Christine May Perandos-Astudillo, alleiandrah@gmail.com

Received

3 November 2021

Accepted

23 December 2021

Published online

28 December 2021

Cite as

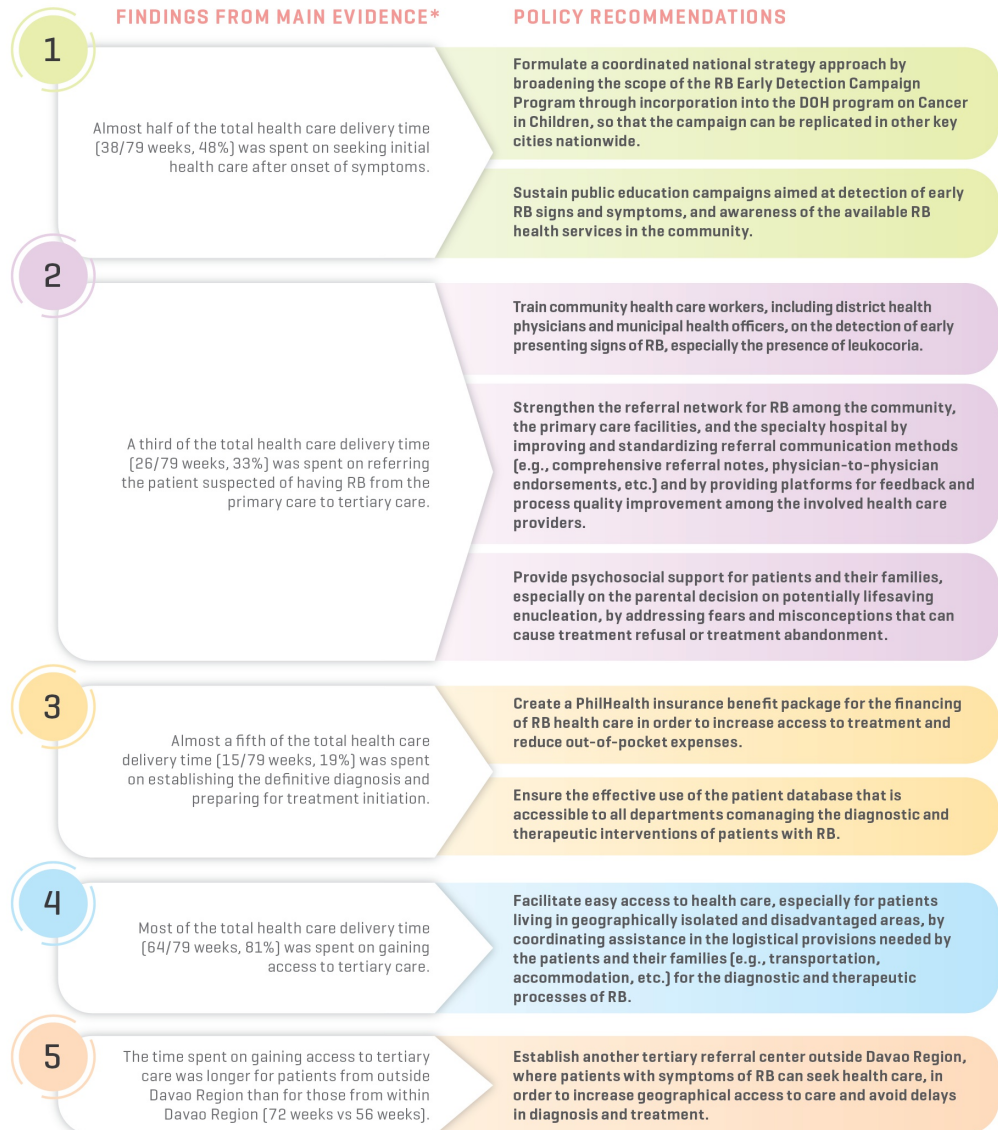
Perandos-Astudillo CM, Roño RC. Health care timeline for patients with retinoblastoma seen in Southern Philippines Medical Center: policy notes. *SPMC J Health Care Serv.* 2021;7(2):8. <http://n2t.net/ark:/76951/jhcs43j4e>

Copyright

© 2021 CM Perandos-Astudillo et al.

Health care timeline for patients with retinoblastoma seen in Southern Philippines Medical Center: policy notes

EVIDENCE to POLICY



*Malabanan-Cabebe CG, Gonzales-Sy JJ. Health care timeline for patients with retinoblastoma seen in Southern Philippines Medical Center: brief report. *SPMC J Health Care Serv.* 2021;7(2):7.



INTRODUCTION

Retinoblastoma (RB), the most common intraocular malignancy in infants and young children,^{1,2} may lead to the loss of one or two

eyes, central nervous system involvement, or even death, if treatment is delayed.³ However, if RB is diagnosed and treated early, patients with the malignancy have a survival rate of

almost 100%.⁴ Delay in diagnosis of RB affects treatment outcomes and prognosis of patients with the disease. With the significant number of RB referrals that result in delays in receiving specialized care in low- and middle-income countries (LMICs)⁵—where most cases occur—global disparities in the outcomes of RB are evident, such that children with RB in LMICs often have poor prognosis.⁶ Difficulty of caregivers and primary health care providers in recognizing the earliest presenting signs of RB also contributes to the delay and can increase the risk of local tumor invasion.⁷

At present, the Department of Health (DOH) has included in its Philippine Cancer Control Program the Cancer in Children Awareness Month, as one of its health advocacies aimed to increase the public's knowledge and understanding of childhood cancer.⁸ In September 2021, the first ever DOH-WHO Cancer Control Stakeholders Virtual Summit was held, with special focus given on childhood cancer.⁹ The DOH program has given emphasis on eight childhood cancers, including RB, that are common in Filipino children.¹⁰

In 2011, the Southern Philippines Medical Center (SPMC) and the National University Hospital in Singapore, in collaboration with the Dana Farber Children's Hospital Cancer Center in Boston and St. Jude Children's Research Hospital in Memphis, joined together to establish the RB Early Detection Campaign Program. This collaborative project started to educate the public on the early signs of RB, established a referral system across Davao City and other regions in Mindanao (Tagum City, General Santos City, Zamboanga City, and Cagayan de Oro City), and developed a multidisciplinary RB management team at SPMC.¹¹ With the opening of a dedicated RB center at SPMC in 2012 as part of the program, the hospital's RB census increased, and the majority of the cases detected were still at the early (intraocular) stage.¹² However, despite the stringent implementation of the program in SPMC, the time interval between onset of symptoms and initiation of therapy among patients with RB has remained protracted.¹³ The aim of this article is to recommend health care policies based on the results of a study on the clinical profile and health care timeline of patients seen in a tertiary hospital in Davao City.

MAIN EVIDENCE

The study of Malabanan-Cabebe and Gonzales-Sy in 2021¹³ was done to determine the profile and health care timeline of patients with RB seen at the SPMC's Ophthalmology Clinic, the only government treatment and referral center for RB patients in Davao Region. The study involved a review of the charts of patients diagnosed as having RB either clinically by a retina specialist or histopathologically post-enucleation, from June 2011 to April 2019. A total of 135 patients, 78 males and 57 females, who consulted at SPMC for diagnostic workup and/or treatment of RB were included. The computed *total health care delivery time* (time from onset of symptoms up to initiation of therapy) among all the patients in the study was 78.70 weeks. Similar findings—in terms of *total health care delivery time*—were noted among patients referred from within (79.44 weeks) and among those from outside Davao Region (78.63 weeks). However, the time to gain access to tertiary care was longer among patients referred from outside Davao Region than among patients referred from within Davao Region (71.52 weeks versus 56.41 weeks, respectively). Our policy recommendations based on specific findings of the study are outlined in the evidence-to-policy diagram.

RELATED EVIDENCE

The effective management of RB hinges on early diagnosis and treatment. The consequences of late diagnosis and treatment may result in advanced disease, characterized by high-risk pathological features, and regional lymph node and systemic metastasis, leading to poor chances of globe salvage and high risk of mortality at the time of presentation.¹⁴ Diagnostic and referral delays are strongly associated with more advanced disease stages, i.e., tumor growth, invasion, and/or extraocular extension.²

Early recognition of symptoms, prompt diagnosis, and timely initiation of treatment give rise to better visual outcomes among patients diagnosed with RB. Increasing the awareness of the possible occurrence of RB—especially among families with hereditary RB—coupled with adequate screening can lead to a higher chance of globe salvage in patients.¹⁸ Early symptom recognition can be achieved through public education, and early consultation with a primary care practitioner can be facilitated by awareness campaigns on

RB health care services available in the locality.

In Kenya, the establishment of the Kenyan National Retinoblastoma Strategy (KNRbS) in 2008 has contributed to the improvement in survival and quality of life of patients with RB across Kenya and Eastern Africa. This international, multidisciplinary, and multisectoral partnership, which includes RB survivors and their families, was instrumental in reducing the number of cases that were lost to follow-up after diagnosis.¹⁵⁻¹⁷ By formulating a national strategy for RB through the DOH program on Cancer in Children, clinical practice guidelines can be created and widely implemented to standardize and improve the quality of care for patients with RB and enhance the patients' chance of survival.

The crucial role of primary care providers in the RB early detection campaign program should be highly emphasized. Pediatricians, primary care physicians, as well as community health workers, need to have adequate knowledge and skills to detect the early symptoms of RB, specifically the presence of leukocoria, in pediatric patients.¹⁹ Workshops and seminars intended for primary care providers and aimed at developing an increased understanding of RB among the participants can be done. Ophthalmologists, on the other hand, may undertake international fellowships on RB Pathology or Clinical RB, which can introduce new perspectives and up-to-date approaches in RB management.¹⁷

Delays in referral to specialized centers can be caused by factors that are physician-related (e.g., inadequate explanation of diagnosis), parent-related (e.g., shopping for a second medical opinion), and/or socio-economic (e.g., lack of funds for health care, geographical location from health care facilities).²

Building the capacity of strategic tertiary centers (other than SPMC) by deploying ophthalmologists who can perform enucleation, and by equipping these centers with adequate histopathology and chemotherapy services, may reduce the primary-to-tertiary-care referral time and decrease the number of RB referrals to SPMC.²⁰ The ultimate goal is the comprehensive management of simple RB cases locally, while complex cases are managed at SPMC.

Facilitating access to subsidized health care financing would ease the financial burden of RB care. Expensive transportation

and/or accommodation costs—especially for patients living in geographically isolated and disadvantaged areas—and out-of-pocket expenses in health care reduce compliance to diagnostic procedures, treatment, and follow-up.¹⁷ As of July 31, 2021, only acute lymphocytic leukemia—among cancers in children—is included in the PhilHealth Z insurance benefit package for catastrophic illnesses.²¹ By creating an insurance benefit package for the management of catastrophic illnesses²²⁻²³ such as RB, families would be relieved of the financial burden of health care due to reduction in out-of-pocket expenses. Resource mobilization—in the form of non-government organization grant funds, private donations, and assistance from political groups—may also help minimize health care costs.

The absence of reliable and efficient record-keeping systems for RB in the presenting centers, and even in referral centers, can also contribute to the delays in RB health care utilization. Different problems in record keeping at the various health facilities (e.g., inability to record the patient's complete address and contact number) can lead to difficulty in tracking patients after referral.⁵ Designing a registry or database that would record important details of patients with RB in real-time and at any point in the referral process can help improve patient follow-up, and in turn, contribute to the general health planning and monitoring for these patients. The database, which should include basic patient demographic and clinical information, family history of RB, clinical staging of both intraocular and extraocular RB, histopathology results, treatment, adverse events, and outcomes,¹³ can be used by the co-managing departments to facilitate collection of routine patient information, and as data source for future case reviews and research projects on RB.

The availability of a reliable health financing scheme facilitates the decision of patients and families to seek health care promptly. On the other hand, comprehensive record-keeping and data sharing among health care providers help expedite the referrals, the coordination of health care, and the monitoring of patients throughout the diagnostic and therapeutic processes.

An effective and multifaceted approach is required in order to achieve a substantial and sustainable increase in the survival of pa-

tients with RB. In general, national strategy is necessary to address the challenges in RB health care delivery, particularly in low-resource settings. Barriers to the care of patients with RB pose a threat in the survival of these patients, hence, a collaborative effort between the health and public sectors is imperative in RB care. Limited health-seeking behavior due to lack of awareness of the disease may be resolved by public education about RB, especially on the recognition of its initial signs. Another issue is the economic barrier to health care access,

which may be addressed through coordinated financial assistance and health insurance. Further, insufficient health care structures and health systems restrict availability of care, which can be resolved by training health care practitioners, strengthening interhospital and intrahospital referral systems, and maintaining a good patient registry or database to improve service efficiency. Together, all these can potentially reduce the duration of RB health care delivery and help achieve optimal outcomes among patients with RB.

Contributors

CMPA and RCR contributed to the conceptualization of this article. All authors wrote the original draft, performed the subsequent revisions, approved the final version, and agreed to be accountable for all aspects of this report.

Article source

Commissioned

Peer review

Internal

Competing interests

None declared

Access and license

This is an Open Access article licensed under the Creative Commons Attribution-NonCommercial 4.0 International License, which allows others to share and adapt the work, provided that derivative works bear appropriate citation to this original work and are not used for commercial purposes. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

1. Fabian ID, Onadim Z, Karaa E, Duncan C, Chowdhury T, Scheimberg I, Ohnuma SI, Reddy MA, Sagoo MS. The management of retinoblastoma. *Oncogene*. 2018 Mar;37(12):1551-1560.
2. Soliman SE, Eldomiaty W, Goweida MB, Dowidar A. Clinical presentation of retinoblastoma in Alexandria: A step toward earlier diagnosis. *Saudi J Ophthalmol*. 2017 Apr-Jun;31(2):80-85.
3. Bowman R. Retinoblastoma: a curable, rare and deadly blinding disease. *Community Eye Health*. 2018;31(101):1-4.
4. Domingo RED, Toledo MSW, Mante BVL. Psychosocial Factors Influencing Parental Decision to Allow or Refuse Potentially Lifesaving Enucleation in Children with Retinoblastoma. *Asia Pac J Oncol Nurs*. 2017 Jul-Sep;4(3):191-196.
5. Nyamori JM, Kimani K, Njuguna MW, Dimaras H. Retinoblastoma referral pattern in Kenya. *Middle East Afr J Ophthalmol*. 2014 Oct-Dec;21(4):321-7.
6. NCI Staff. For children with retinoblastoma, disparities seen across the globe. 2020 Mar 12 [cited 2021 Dec 28]. In: National Cancer Institute [Internet]. Maryland: National Cancer Institute. c2021 - . [about 1 screen]. Available from: <https://www.cancer.gov/news-events/cancer-currents-blog/2020/retinoblastoma-global-disparities-low-middle-income-countries>.
7. Goddard AG, Kingston JE, Hungerford JL. Delay in diagnosis of retinoblastoma: risk factors and treatment outcome. *Br J Ophthalmol*. 1999 Dec;83(12):1320-3.
8. Department of Health. Philippine cancer control program. [cited 2021 Dec 28]. In: Department of Health [Internet]. Manila: Department of Health. c2021 - . [about 1 screen]. Available from: <https://doh.gov.ph/philippine-cancer-control-program>.
9. Department of Health. DOH, who to hold 1st cancer control stakeholders virtual summit with special focus on childhood cancer. 2021 Sep 23 [cited 2021 Dec 28]. In: Department of Health [Internet]. Manila: Department of Health. c2021 - . [about 1 screen]. Available from: <https://doh.gov.ph/press-release/DOH-WHO-TO-HOLD-1ST-CANCER-CONTROL-STAKEHOLDERS-VIRTUAL-SUMMIT-WITH-SPECIAL-FOCUS-ON-CHILDHOOD-CANCER>.
10. Department of Health. Cancer in children. [cited 2021 Dec 28]. In: Department of Health [Internet]. Manila: Department of Health. c2021 - . [about 1 screen]. Available from: <https://doh.gov.ph/Health-Advisory/Cancer-in-Children>.
11. National University Hospital. Overseas outreach. [cited 2021 Dec 28]. In: National University Hospital [Internet]. Singapore: National University Health System. c2021 - . [about 1 screen]. Available from: <https://www.nuh.com.sg/our-services/Specialties/Paediatrics/Pages/Overseas-Outreach.aspx>.
12. Carbone MV, Diez CL, Dolendo MC. The number of referrals on retinoblastoma cases before and after the early detection campaign in Southern Philippines Medical Center Children's Cancer and Blood Diseases Unit (SPMC-CCBDU) [unpublished]. Davao: Southern Philippines Medical Center; 2017.
13. Malabanan-Cabebe CG, Gonzales-Sy JJ. Health care timeline for patients with retinoblastoma seen in Southern Philippines Medical Center: brief report. *SPMC J Health Care Serv*. 2021;7(2):7.
14. Kaliki S, Ji X, Zou Y, Rashid R, Sultana S, Taju Sherief S, et al. Lag Time between Onset of First Symptom and Treatment of Retinoblastoma: An International Collaborative Study of 692 Patients from 10 Countries. *Cancers (Basel)*. 2021 Apr 19;13(8):1956.
15. World Eye Cancer Hope. Kenya National RB Strategy. [cited 2021 Dec 28]. In: World Eye Cancer Hope [Internet]. England: World Eye Cancer Hope. c2020 - . [about 1 screen]. Available from: <https://wechope.org/programs/ratis-challenge/kenyan-rb-strategy/>.
16. Qaiser S, Limo A, Gichana J, Kimani K, Githanga J, Waweru W, Dimba EA, Dimaras H. Design and Implementation of the Retinoblastoma Collaborative Laboratory. *Ocul Oncol Pathol*. 2017 Jan;3(1):73-82.

17. Hill JA, Kimani K, White A, Barasa F, Livingstone M, Gallie BL, et al. Achieving optimal cancer outcomes in East Africa through multidisciplinary partnership: a case study of the Kenyan National Retinoblastoma Strategy group. *Global Health*. 2016 May 26;12(1):23.
18. Al-Nawaiseh I, Ghanem AQ, Yousef YA. Familial Retinoblastoma: Raised Awareness Improves Early Diagnosis and Outcome. *J Ophthalmol*. 2017;2017:5053961. doi: 10.1155/2017/5053961. Epub 2017 Mar 2.
19. Rodriguez-Galindo C, Wilson MW, Chantada G, Fu L, Qaddoumi I, Antoneli C, et al. Retinoblastoma: one world, one vision. *Pediatrics*. 2008 Sep;122(3):e763-70.
20. Dimaras H, Kimani K, Dimba EAO, Gronsdahl P, White A, Chan HSL, et al. Retinoblastoma. *Lancet*. 2012 Apr;379(9824):1436-46.
21. Department of Health. Contracted health care institutions for Z-Benefit Package as of November 15, 2021. [cited 2021 Dec 28]. In: Department of Health [Internet]. Manila: Department of Health. c2021 - . 2 p. [about 1 screen]. Available from: https://www.philhealth.gov.ph/partners/providers/institutional/accredited/zbnfts_11152021.pdf.
22. Department of Health, Republic of the Philippines. Governing policies on PhilHealth benefit package for case Type Z, PhilHealth Circular No. 029, s-2012 (2012 Jun 17).
23. Department of Health, Republic of the Philippines. Implementing guidelines on the Z benefit, PhilHealth Circular No. 048, s-2012 (2012 Oct 3).

Southern Philippines Medical Center Journal of Health Care Services Editors

Editor in Chief: Alvin S Concha • **Associate Editors:** Christine May Perandos-Astudillo, Rodel C Roño, Melivea I Melgazo, Seurinane Sean B Española

Managing Editor: Clarence Xlasi D Ladrero • **Layout Editor:** Clarence Xlasi D Ladrero

SPMC JHCS OFFICE Research Utilization and Publication Unit, Acacia Room, Level 3 Outpatient Building, Southern Philippines Medical Center, JP Laurel Avenue, Davao City, Philippines

Landline (+6382) 2272731 loc 4127 • **Website** www.spmcjournal.com • **Email** spmcpapers@gmail.com