

ORIGINAL ARTICLE

Out-of-pocket expenditure in childhood cancer during the COVID-19 pandemic in Peru

Gastos de bolsillo en cáncer infantil durante la pandemia de COVID-19 en Perú

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OPEN ACCES

Cite as:

Maradiegue E, Maza I, Chavez S, Aranda L, Pascual C, García H, et al. Out-of-pocket expenditure in childhood cancer during the COVID-19 pandemic in Peru. Onkoresearch. 2022;1(1):14-20

Received:

11/07/2022

Approved:

30/09/2022

Author's contributions:

EM and LV participated in the conceptualization, investigation, supporting, analysis, methodology, writing and editing of the original draft; IM took part in the conceptualization^a supporting, investigation; SC, LA, CP, HG, RP^cR and AB contributed to the conceptualization and supporting; MG took part in the investigation and supporting; IH contributed to the conceptualization and supporting; CM, MT and EM participated in the conceptualization and supporting; VP participated in the conceptualization, supporting and investigation.

Financing:

None.

Conflicts of interest:

The authors declare that there are no conflicts of interest.

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ABSTRACT

Background: The COVID-19 pandemic has led to unprecedented economic and health vulnerability and inequities globally. **Objective:** This study examines the out-of-pocket expenses assumed by parents of children and adolescents with cancer in Peru during the COVID-19 pandemic and compares them to those corresponding to the pre-COVID era. **Materials and methods:** We conducted a cross-sectional survey of parents and caregivers of pediatric cancer patients who were cared for in public and private institutions between October and November 2020. All of them gave their consent before completing the survey. Respondent parents of children diagnosed before March 2020 were considered the pre-COVID-19 pandemic group, whereas if the definitive diagnosis was made after this date, it was classified as part of the COVID-19 group. **Results:** A total of 222 parents and caregivers of children with cancer responded to the survey. Almost half of the respondents lived in Lima. The average monthly family income was USD 388.4 and USD 314.7 before and during the COVID-19 pandemic. The average expenditure was USD 487.0 (SD, 453.5) and USD 415 (SD, 414.5) before and during the COVID-19 pandemic, before the cancer diagnosis. The average expenditure was USD 454.6 (SD, 406.7) and USD 387.5 (SD, 323.4) before and during the COVID-19 pandemic after a cancer diagnosis. In the COVID-19 group, the rate of catastrophic expenditure on these families was 86% before the definitive diagnosis and 75% after the cancer diagnosis. According to the type of cancer, families with a child diagnosed with a solid tumor had significantly higher out-of-pocket expenses than a leukemia than those with a child with leukemia prior to their diagnosis. **Conclusion:** Our study suggests that high out-of-pocket

health expenses were frequent in families with a child with cancer in Peru during the COVID-19 pandemic. It is possible to infer that this situation was aggravated by the decrease in economic income of most families due to the disruption of formal and informal employment.

Keywords

Covid-19 pandemic; Health insurance; out-of-pocket; universal coverage (source: MeSH NLM).

RESUMEN

Antecedentes: La pandemia de COVID-19 ha generado vulnerabilidad e inequidades económicas y sanitarias sin precedentes en todo el mundo. **Objetivo:** este estudio examina los gastos de bolsillo asumidos por los padres de niños y adolescentes con cáncer en Perú durante la pandemia de COVID-19 y los compara con la era pre-COVID. **Materiales y métodos:** Realizamos una encuesta transversal a padres y cuidadores de pacientes oncológicos pediátricos atendidos en instituciones públicas y privadas entre octubre y noviembre de 2020. Todos dieron su consentimiento antes de contestar la encuesta. Los padres encuestados de niños diagnosticados antes de marzo de 2020 fueron considerados el grupo pre-pandemia de COVID-19, mientras que si el se realizó el diagnóstico definitivo después de esta fecha, se clasificó como parte del grupo COVID-19. **Resultados:** Un total de 222 padres y cuidadores de niños con cáncer respondieron a la encuesta. Casi la mitad de los encuestados vivían en Lima. El ingreso familiar mensual promedio fue de USD 388,4 y USD 314,7 antes y durante la pandemia de COVID-19. El gasto promedio antes del diagnóstico de cáncer fue de USD 487,0 (SD, 453,5) y USD 415 (SD, 414,5) antes y durante la pandemia de COVID-19. El gasto promedio después del diagnóstico de cáncer fue de USD 454,6 (SD, 406,7) y USD 387,5 (SD, 323,4) antes y durante la pandemia de COVID-19. En el grupo de COVID-19, la tasa de gasto catastrófico de estas familias fue del 86% antes del diagnóstico definitivo y del 75% después del diagnóstico de cáncer. Según el tipo de cáncer, las familias con un niño diagnosticado con un tumor sólido tuvieron gastos de bolsillo significativamente más altos que un niño con leucemia antes de su diagnóstico. **Conclusión:** Nuestro estudio sugiere que los altos gastos de bolsillo en salud fueron frecuentes en las familias que tienen un hijo con cáncer en Perú durante la pandemia de COVID-19. Es posible inferir que esta situación se agravó por la disminución de los ingresos económicos de la mayoría de las familias debido a la disrupción del empleo formal e informal.

Palabras clave

Pandemia de COVID-19; Seguro de salud; gasto de bolsillo; Cobertura universal (fuente: DeCS BIREME).

INTRODUCTION

The COVID-19 pandemic is causing a significant social and economic impact in developing countries, as well as increasing health disparities and inequities. Delivering care for cancer patients during this crisis is challenging, given the competing priorities in public health. Pediatric

cancer services have been significantly disrupted during the COVID-19 pandemic in many countries of Latin America, which has been more severe in territories with low healthcare expenditure ⁽¹⁾. In Peru, an upper-middle-income country, COVID-19 infection in children with cancer made visible significant income inequalities affecting the access to health services, leading to worse outcomes ⁽²⁾.



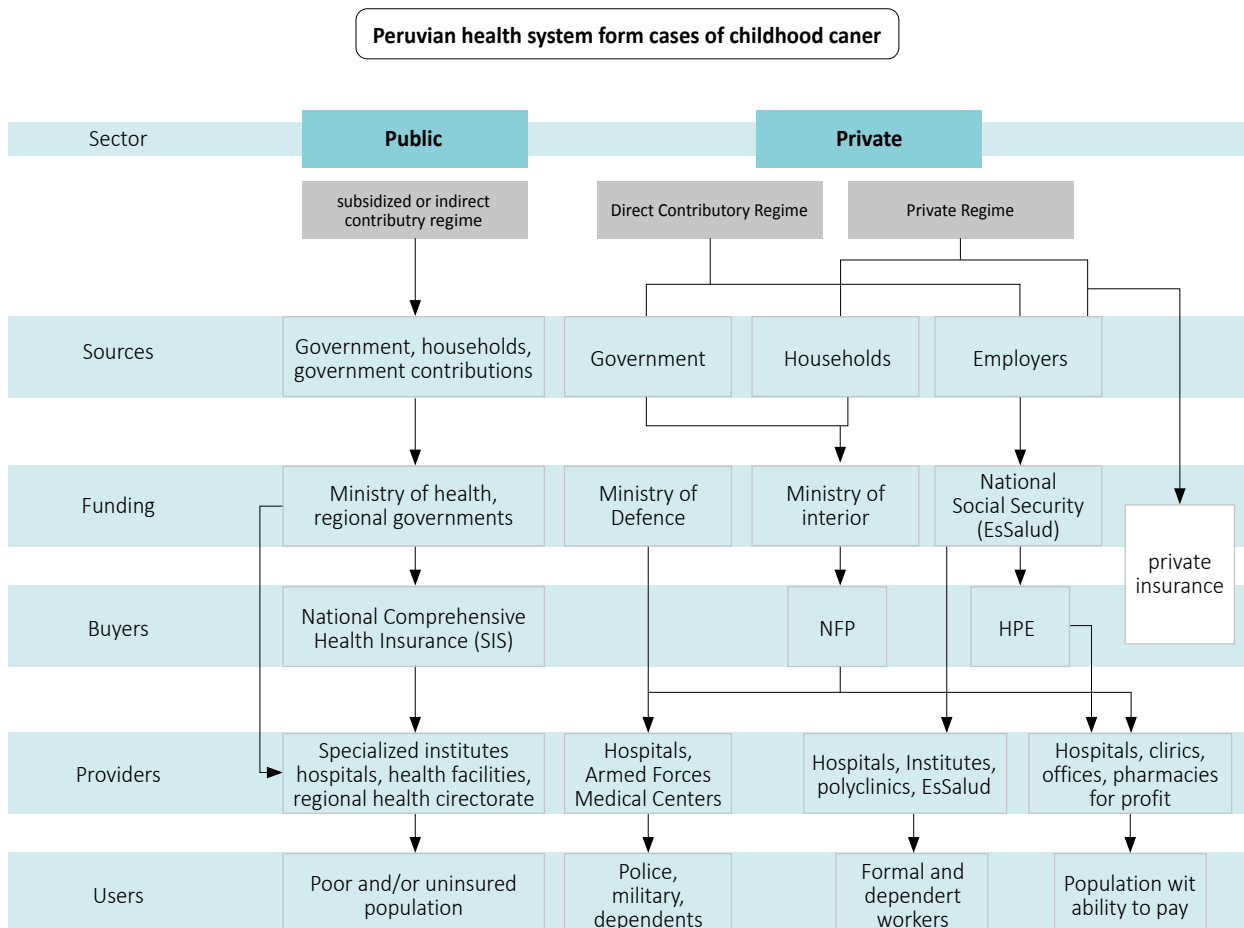
Out-of-pocket (OOP) health expenditure is defined as direct payments made by individuals to health care providers at the time-of-service use, including fees charged for medical consultations and procedures, cost of medicines, supplies, and others⁽³⁾. Health and life are at risk whenever the health expenditure is equal to or exceeding 40% of a household's non-subsistence income, defined as catastrophic health expenditure⁽⁴⁾. In Peru, despite increasing the coverage of the national insurance system (*Integral Health Insurance-SIS*), OOP spending remains high among patients without any affiliation to public insurance⁽⁵⁾.

A close association of OOP expenditures with health inequalities has been described in developing countries⁽⁶⁾, although evidence related to cancer treatment is still scarce. Moreover, there is a lack of evidence of the OOP variations during the COVID-19 pandemic. This study aims to examine the OOP expenses assumed by parents of children and adolescents with cancer in Peru during the COVID-19 pandemic and compare this to the pre-COVID era.

MATERIALS AND METHODS

Study design and setting

The Peruvian health system is divided into public and private facilities (Figure 1). Public centers work as *subsidized or indirect contributory regimes* where the government offers health services to the uninsured population through the National Comprehensive Health Insurance (SIS), being its target population individuals living in conditions of poverty and extreme poverty. This mechanism included the network of facilities of the Ministry of Health (MINSA), hospitals and specialized institutes located nationwide. The *direct contributory regime* includes the national Social Security (EsSalud) and private facilities (EPS). EsSalud offers health services to the employed contributors and their families. The armed forces (FFAA) and the National Police of Peru (PNP) have their separate health subsystem. Private facilities include private insurers, private clinics, medical centers and polyclinics. The resulting system contains multiple providers of services and insurance,



FISSAL: Intangible Solidarity in Health Fund; SIS: Integral Health Insurance; NPP: National Police of Peru; HPE: Health Provider Entities.

Figure 1. Peruvian health system for cases of childhood cancer.

often performing functions with a high degree of overlap and little coordination.

We conducted a cross-sectional survey with parents of pediatric cancer patients who are cared for in the public and private systems (National Institute of Neoplastic Diseases, National Institute of Child Health, Rebagliati National Hospital, Almenara National Hospital, Armed Forces Hospital, Delgado and Anglo-American Clinic) between October and November of 2020. All of them gave their consent before answering the survey.

Subjects

Our study population was composed of parents of children and adolescents (0 to 18 years old) diagnosed with cancer between January 2015 and July 2020 and signed their informed consent as participants. This time frame was chosen due to the economic stability of the local currency during the last five years, which would allow for an adequate analysis. Respondent parents of children diagnosed before March 2020 were considered the pre-COVID-19 pandemic group, whereas for definitive diagnoses made after this date, they were classified as part of the COVID-19 pandemic group.

Study definitions

Catastrophic expenditure was defined according to the World Health Organization (WHO) as the occurrence of expenditure in childhood cancer care equal or greater to 40% of the total non-subsistence household income (capacity to pay). Expenditures were classified as medical (diagnostic tests and medication) and extra-medical (transportation, food, and lodging). The catastrophic expenditure rate will be defined as the proportion of families who experience catastrophic expenditure out of all families included in the study.

Instrument and procedure

Our instrument was a survey. The first part of it consisted of questions about the child's socio-demographic circumstances and clinical information with cancer. The second part of the survey included questions regarding the family income and expenditure before and after the child's definitive diagnosis, along with specific areas of spending. OOP costs included all expenses related to the childhood cancer care paid by the parents and not reimbursed by the hospital. The survey was distributed electronically and in printed format through contacts obtained from hospital records in public and private pediatric oncology outpatient and inpatient settings.

Data collection

The survey was applied online through Google Forms and in person, assisted by the researchers. After that, it was

downloaded into a database, which was subsequently tabulated and analyzed.

Data analysis

The analysis included a baseline comparison of parents and caregivers of children with cancer in the pre-COVID-19 group or COVID-19 group. Medians and interquartile ratios (IQR) were calculated for the continuous variables, and percentages were calculated for categorical measures. Statistical differences between the pre and COVID-19 groups were determined with chi-square tests for categorical variables and t-test for continuous variables. The differences between both groups were significant for the two-sided p-value (less than 0.05). All the analyses were carried out using the Stata 16.0 software.

Ethical approval

The survey did not provide identifiable data of the patients; hence, an institutional review board evaluation was not necessary. Regardless of the aforementioned points, an informed consent form was signed by the respondents.

RESULTS

A total of 222 parents and caregivers of children with cancer responded to the survey. The majority of caregivers were mothers (84.3%) and married or cohabiting (69.7%). Almost half of the respondents (47.5%) were originally from Lima and 52.5% lived outside the capital. The most frequent type of cancer in children was leukemia (57%). Ninety-seven percent of respondents had insurance (SIS, 60.4%; Social Security of Peru, 33%, Armed Forces, 1.7%; and private, 2.2%), whereas 3% did not have any type of insurance. Most mothers were unemployed (58.1%), whereas 79.2% of fathers had independent or dependent work (54% and 25.2%, respectively). (Table 1) Age, relationship with the patient, type of cancer diagnosis, marital status, residency type, and home location were not significantly different between the pre-COVID-19 and COVID-19 groups. However, in the COVID-19 group, there was a considerably higher proportion of patients affiliated to the national public insurance and a decrease in the proportion of patients covered by the Social Security of Peru ($p=0.006$).

Seventy-five percent of the respondents' children had a cancer diagnosis before starting the COVID-19 pandemic in Peru (before March 2020). Responses included cases diagnosed since 2015. The average monthly family income was USD 388.4 (SD, 339.2) and USD 314.7 (SD, 310.3) before and during the COVID-19 pandemic. The average expenditure was USD 487.0 (SD, 453.5) and USD 415 (SD, 414.5) before and during the COVID-19 pandemic, before

Table 1. Baseline characteristics of the survey respondents (parents and caregivers of children with cancer in Peru) according to the time that the child was diagnosed (before March 2020, pre COVID-19 or after March 2020, COVID-19 era) (N=222).

Variables ^a	Pre COVID-19 (n=166)	COVID-19 (n=56)	p-value
Age, median (range)	35 (17,52)	37 (19,61)	0.45
Family member	Mother (84.3%) Father (12.7%) Other (3%)	Mother (83.9%) Father (7.2%) Other (8.9%)	0.32
Type of cancer diagnosis	Leukemia (60.6%) Solid tumors (39.4%)	Leukemia (56.9%) Solid tumors (43.1%)	0.62
Stage at diagnosis	I-II (31.3%) III- IV (68.7%)	I-II (37.5%) III- IV (62.5%)	
Marital status	Married (67.7%) Divorced (30.5%) Widow (1.8%)	Married (75.9%) Divorced (22.4%) Widow (1.7%)	0.49
Residency type	Rural (36.7%) Urban (63.3%)	Rural (31.1%) Urban (68.9%)	0.44
Home location	Lima (46.3%) Regions (53.7%)	Lima (50.9%) Regions (49.1%)	0.55
Type of insurance	Public, Seguro Integral de Salud (SIS) (56.2%) Public, Social Security of Peru (Essalud) (39.1%) Armed Forces (1.2%) Private (2.3%) No insurance (1.2%)	Public, Seguro Integral de Salud (SIS) (70.7%) Public, Social Security of Peru (Essalud) (17.3%) Armed Forces (3.5%) Private (1.7%) No insurance (6.9%)	0.006
Employment, mother	Independent or informal (25%) Not working (53.6%) Formal job (27.3%)	Independent or informal (19%) Not working (68.9%) Formal job (20.7%)	0.10
Employment, father	Independent or informal (55.8%) Not working (16.9%)	Independent or informal (51.7%) Not working (27.6%)	0.19
Monthly family income, average (SD)	388.4 (±339.2)	314.7 (±310.3)	0.17
OOP expenses, average (SD), before the diagnosis	487.0 (±453.5)	415 (±414.5)	0.35
OOP expenses, average (SD), after the diagnosis	454.6 (±406.7)	387.5 (±323.4)	0.26

^a were missing in marital status, residency type and location in 3 cases, employment in 5 cases for mother and 7 cases in fathers, family income in 11 cases and OOP in 13 and 12 cases, before and after diagnosis, respectively.

OOP: out-of-pocket; SD: standard deviation

the cancer diagnosis. The average expenditure was USD 454.6 (SD, 406.7) and USD 387.5 (SD, 323.4) before and during the COVID-19 pandemic after a cancer diagnosis. There were no significant differences between the pre-COVID-19 and COVID-19 groups in the OOP costs.

In the COVID-19 group, the rate of catastrophic expenditure on these families was 86% before the definitive diagnosis and 75% after the cancer diagnosis. OOP expenses before the cancer diagnosis were allocated to medical and laboratory consultations, medicines, food,

transportation, and accommodation. (Figure 2) According to the type of cancer, families of a child diagnosed with a solid tumor had significantly higher OOP expenses than a leukemia diagnosis before the diagnosis. ($p=0.0007$) (Figure 3).

DISCUSSION

Our study reveals the high burden of OOP expenditure in families of children with cancer in Peru, despite having free

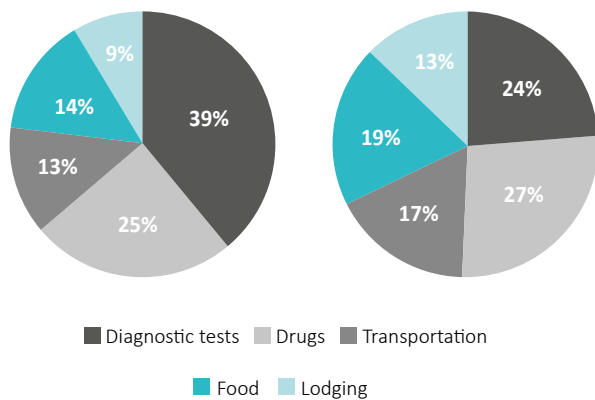


Figure 2. Concepts of out-of-pocket health expenses before and after diagnosis.

treatment insurance. As a result of the economic impact of the COVID-19 pandemic, the average income of Peruvian families was reduced, mainly due to unemployment or informal jobs. This crisis led to a significant reduction in the proportion of families covered by the Social Security of Peru, as employers are obligated to make monthly health contributions. The OOP expenditures of the families of children with cancer remained high before and during the COVID-19 pandemic, above the expected family income leading to catastrophic spending.

Several studies address OOP spending on health in Peru (7-9); however, there is no specific data for children with cancer. In 2016, OOP spending in Peru was 28% as a percentage of total health spending, considerably higher than the WHO standard (between 15% and 20%) (10). In 2018, the OOP health expenditure of Peruvians was 11,000 million soles (nearly 3000 million dollars) per year, of which 39% was spent on medicines, according to the National Household Survey (11). OOP spending was positively associated with a lack of affiliation to public insurance in poor households (5). Although a national health policy named Intangible Solidarity in Health Fund (Fissal) covers the high cost of cancer treatment for seven types of cancer (leukemia, lymphomas, breast, cervical, colon, stomach, and prostate cancer), the expenses of having a child with cancer in Peru is still leading to catastrophic costs in Peruvian families.

Some causes of the high burden of OOP expenditure in families of children with cancer include that the insurance is activated once the cancer diagnosis is confirmed, leading to families incurring in OOP expenses to establish the diagnosis. Additionally, 90% of children with cancer are treated in Lima, the capital of Peru. Centralizing the institutions that provide childhood cancer care in Peru causes most parents and caregivers to cover the high cost of transferring patients from the regions to Lima. Finally,

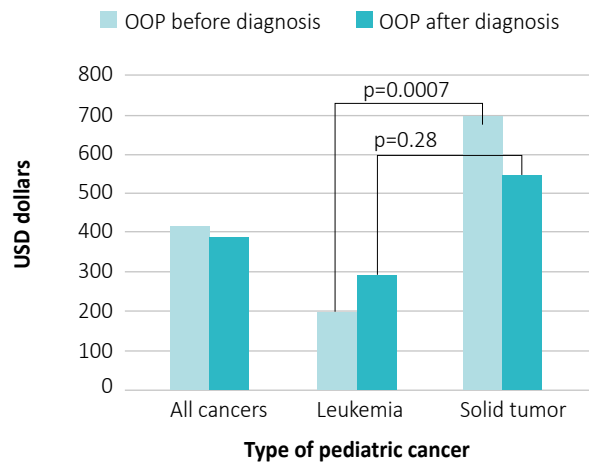


Figure 3. OOP according to the type of pediatric cancer.

patients might require diagnostic studies or high-cost drugs that are not covered by public insurance. A specific national policy for the protection of this vulnerable population has been recently developed with the approval of the Childhood Cancer Law in Peru, which guarantees the universal coverage of cancer care from the moment in which a diagnosis of childhood cancer is suspected, provides social protection for parents of children with cancer and favor the improvement of health services aiming at a timely and quality care of these children (12).

Among the areas of OOP expenses found in our study, this could be compared with the study by Ahuja et al., which suggests that families incur direct medical and non-medical costs (food, lodging, and transportation) leading to substantial, imposing a catastrophic burden and affecting employment, education, and housing (13). These differ in other studies from high-income countries such as Canada. The highest costs of families of children with cancer are transportation and time allocated to unpaid activities (14). Parents of children diagnosed with a solid malignant tumor had higher OOP expenses when compared to leukemia. This finding could be likely explained by the high cost of medical laboratory and imaging tests needed before diagnosing most causes of solid tumors (Wilms tumors, neuroblastoma, and sarcomas). Interestingly, the median health expenditure of the families was higher than the median family income. This could be explained by the fact that many of the families in our country had to gain extra income from other activities, through external support (such as foundations), bank loans, among others. This phenomenon has been previously described in other contexts of low- and middle-income countries, especially related to cancer treatments (15,16).

A limitation of this study is that, due to the cross-sectional nature of the survey, causal relationships cannot be established and the possible memory bias on the part

of the respondent, typical of survey-based studies. We could not establish a comparison of the expenditures between the pre-pandemic and pandemic groups after the diagnosis as OOP is likely to be very different related to a different stage of progression and treatment. Additionally, out-of-pocket spending on medicines and supplies can present individual, family, or a combination of both levels not collected by the survey. An important limitation is the lack of details related to the expenses according to the types of drugs, whether innovative new cancer drugs or traditional chemotherapies. This could impact OOP in a significant manner as there is a huge cost difference between the types of drugs received by patients. Finally, this study does not have the approval of the ethics committee, since it does not collect direct information from the patient.

As a strength, this study provides evidence of the high burden of OOP on families of children with cancer in low- and middle-income countries, especially during such a relevant era of COVID-19. Interestingly, we observed a highly inequitable distribution of employment among parents according to gender, suggesting that most mothers did not work or probably resigned from their jobs to attend to their children during their children's difficult diagnosis and treatment.

In conclusion, our study observes that high OOP health expenditures were frequent in families who have a child with cancer in Peru during the COVID-19 pandemic. It is possible to infer that this situation was aggravated by the decrease in economic income of most families due to the disruption of formal and informal employment. Further studies are needed to confirm these findings.

Acknowledgments

Our thanks to Annaly Benavente for her commitment and dedication to the benefit of children with cancer during her life and to the members of the foundation's committee of the Global Initiative for Childhood Cancer in Peru.

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