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Title: An Analysis of Palliative Care Development in Africa: A Ranking based on Region-Specific Macro-Indicators

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ABSTRACT

Context: To date, there is no study comparing palliative care (PC) development among African countries.

Objective: To analyze comparatively PC development in African countries based on region-specific indicators.

Methods: Data were obtained from the APCA Atlas of PC in Africa and a comparative analysis conducted. Nineteen indicators were developed and defined through qualitative interviews with African PC experts and a two-round modified Delphi consensus process with international experts on global PC indicators. Indicators were grouped by the WHO public health strategy for PC dimensions. These indicators were then sent as a survey to key informants in 52/54 African countries. Through an expert weighting process and ratings from the modified Delphi, weights were assigned to each indicator.

Results: Surveys were received from 89% (48/54) of African countries. The top three countries in overall PC development were, in order, Uganda, South Africa, and Kenya. Variability existed by dimension. The top three countries in specialized services were Uganda, South Africa, and Nigeria; in policies, it was Botswana followed by parity among Ethiopia, Rwanda, and Swaziland; in medicines, it was Swaziland, South Africa, then Malawi; in education, it was equivalent between Uganda and Kenya, then Ghana and Zambia.

Conclusion: Uganda, South Africa, and Kenya are the highest performing countries and were the only ones with composite scores greater than 0.5 (50%). However, not one country universally supersedes all others across all four PC dimensions. The breakdown of rankings by dimension highlights where even high-performing African countries can focus their efforts to further PC development.

Abstract Word Count: 250

Keywords: palliative care development, Africa, atlas, public health, ranking

Running Title: Palliative Care Development Ranking in Africa
Introduction

The World Health Organization (WHO) Africa Region lags in world averages for health and human development(1). Regional average life expectancy is 53 years, approximately 15 fewer years than the global average(1). HIV/AIDS in sub-Saharan Africa continues to be the leading cause of disability(2) and its prevalence among African adults is by far the greatest burden worldwide(1). The region, as a whole, has the highest total burden of disease compared with other WHO regions, and there has been a rapid rise in risk factors for chronic and non-communicable diseases(3).

Given the region has the highest rates of mortality, morbidity and disease burden of all WHO regions(1), hospice and palliative care (HPC) development across the continent is even more pertinent to patient care. Despite the lack of available treatments, patients should be able to, at a minimum, die a pain-free and symptom-controlled death. In fact, HPC services in Africa have grown in the past decade; 15 countries moved to higher levels of palliative care (PC) development from 2006 to 2011(4, 5). However, half of African countries were categorized into Level 1 (no known PC activity) and Level 2 (capacity building, i.e., no services yet identified) and, therefore, there is still much progress to be made on the continent.

Global mapping projects have studied PC development in Africa. The world map of PC, mentioned above, is one such project, that categorized countries into four development levels(4). The Economist Intelligence Unit used a series of 24 indicators to rank countries in their Quality of Death Index 2015(6). However, the world map does not provide specific development indicators for each country; rather, it provides a large overview and categorization of countries into development levels(4), and the Economist, despite utilizing a large group of indicators, only covers 13 African countries(6).

Regional atlas projects also exist that study in-depth the state of PC development in various world regions. The EAPC Atlas of PC in Europe,(7, 8) the ALCP Atlas of PC in Latin America,(9) and the Atlas of PC in the Eastern Mediterranean Region(10) are examples of such mapping projects and are important advocacy tools for their respective regions. Such atlases have been conducted in partnership with regional PC networks and associations, involving experts in PC within the regions.

The methodology used in the EAPC and ALCP Atlases were reviewed and improved to build an APCA (African PC Association) Atlas of PC in Africa.(11) As in other regional atlas projects, the current project was conducted with the regional association for palliative care: the APCA. The African Atlas utilized a rigorous methodology of in-depth interviews with in-country experts on the continent followed by a rating system and a two-round Delphi consensus process to derive a set of African-specific indicators to measure PC development on the continent(12). This manuscript presents a secondary analysis of data obtained for the APCA Atlas, including a ranking of African countries, to provide an overview of their progress in PC development. Other
similar ranking exercises have previously been completed with results from the EAPC Atlas of PC in Europe.(13) A categorization system on PC development exists in the world map, but a ranking gives a clearer view of where countries are relative to each other in the same region and the dimensions in which certain countries are stronger or weaker.

Methods

The primary survey: Atlas of PC in Africa

The APCA Atlas of PC in Africa was developed in multiple stages. The initial stages deriving indicators utilized in this project have been described elsewhere(12). In brief, 16 interviews with in-country experts in Africa were conducted(14), indicators were derived from the analyzed transcribed interviews, and the in-country experts rated the indicators for feasibility and validity on a scale from 1 to 4. Those scoring 3 or above then went through a two-round Delphi process with a 14-member committee of international experts on indicators who rated the indicators from 1 to 9 for importance in Africa. The final indicators were organized into the WHO public health strategy dimensions for PC(15) and then ranked by the project team (co-authors), with the highest scoring indicators in each dimension chosen as the final set of 19 indicators used to obtain information for this study(12, 16).

A network of key informants in PC in Africa was constructed based on the APCA’s knowledge and recommendation, with each contacted to participate in the project via email. Those who replied stating their interest were sent the survey containing the 19 indicators on national PC development within their respective countries.

Finally, an Expert Dimension Weighting Process, composed of four of the co-authors who are experts on PC development in Africa and four members of the APCA Board of Directors (eight members total) weighted each of the four dimension of the WHO public health strategy for palliative care (PC specialized services, PC policies, PC medicines, and PC education)(15), dividing up the weights out of 100% according to the following guiding question: “How do the dimensions contribute relatively to current PC development in Africa?”

The study was approved by three Institutional Review Boards: the Icahn School of Medicine at Mount Sinai (IRB-16-00242), the University of Navarra (2016.054), and Mildmay Uganda Ethics Review Board (RECREF 0505-2016). Informed consent was received from all participants participating in each step of the study.

Indicators Included in Rankings

Indicators were grouped into four categories, according to the WHO public health strategy for PC and cleaned and calculated by the first author, as outlined below. Development indicators are defined as indicators that measure processes, structures, policies, and resources
that support the delivery of palliative care. Due to missing data, Libya and Angola were excluded from this analysis.

**PC Specialized Services:** Within services, the indicator measuring the total number of HPC services in the country was correlated with the indicators measuring the number of pediatric-specific HPC services, number of home-based PC services in hospices, and the number of PC inpatient units in hospitals. The Spearman correlations were statistically significant (p<0.001) and strong (0.73, 0.64, and 0.79, respectively). Furthermore, the two indicators measuring the number of PC patients cared for in the last year, and the proportion of regions or districts with PC services, had a large number of missing data points and, therefore, were excluded from the analysis. In the end, the only one indicator measuring the total number of HPC services in the country was included in the analysis. The indicator was normalized by dividing all countries by the number of services from the country with the highest number of services. Of note, “HPC services: is more thoroughly defined in the APCA Atlas of Palliative Care in Africa(16).

**Policies.** All policy variables were utilized. Where there were missing data, the authors assumed there was no available or functioning policy in that country; if the PC expert in the country was unable to state whether there was or was not a particular policy then, in effect, the policy was not functioning or not available to the public.

**Medicines.** The indicator measuring annual morphine consumption was normalized by dividing each country’s consumption by the consumption of the highest country (13.24 mg/capita/year South Africa). Morphine consumption was the only variable not obtained from experts but rather from the International Narcotics Control Board. Similarly, if there were no available data on medicine policies, a similar assumption was made that the policy did not exist or was not functioning or available to the public for the analysis.

**Education.** The indicators measuring proportion of schools with palliative care education in medical and nursing schools (mandatory and optional) were both modified to dichotomous variables to account for missing data. If there was presence of any type of medical education, the country was given a score of 1, and 0 if there was not; the same was done for nursing education.

**Calculation of Points and Rank Order**

For theoretical reasons, weighting of indicators is important. In Africa, for example, the weighting of specialized services in the context of PC development across the continent, may be relatively more important than, for example, PC policies due to the realities of implementation and accessibility of such policies. The use of different weights can vastly change rankings of how countries fare in terms of PC development compared to one another and, therefore, we used a rigorous methodology of determining the weights of the indicators we collected through the consensus of experts in African PC development. As mentioned above, data were obtained from the APCA Atlas of PC in Africa(16).
Using the two-round Delphi process ratings from 1 to 9 mentioned above (12), proportional weights were given to each indicator within each WHO dimension (e.g., if there were three indicators rated as 8, 9, 9, then the sum of the three indicators, 26, was used as a denominator, and each indicator was assigned a percentage according to the rating proportional to the denominator).

The Expert Dimension Weighting Process resulted in an overall weight of 35.6% for PC specialized services, 13.8% for PC policies, 25% for PC medicines, and 25.6% for PC education. Figure 1 shows the weights of the individual indicators within each dimension. The overall rank was based on the sum of the composites of the WHO dimensions.

Results

Of the 54 countries included in the study, 48 (88%) responded to the survey. No key informants were identified in two countries (Cape Verde and Guinea-Bissau), and we received no responses from four countries (Chad, Djibouti, Seychelles, and Somalia). Of the 48 countries, 19 (40%) had two respondents, and 29 (60%) had one.

Summary of Data

PC Specialized Services. More than 75% of the total number of hospice and PC services are concentrated in the five countries with the highest reported number of services (Uganda, South Africa, Kenya, Nigeria, and Tanzania), and one-fifth (Burkina Faso, Central African Republic, Comoros, Equatorial Guinea, Eritrea, Lesotho, Liberia, Madagascar, Mali, Republic of Congo, Sao Tome & Principe, and South Sudan) of countries responding to the survey had zero reported HPC services.

Policies. Of the 12 countries reporting a stand-alone PC plan or program, most (75%) are similarly located in southern and eastern Africa. Half (24/48) of responding countries indicated having a section for PC in the national cancer or non-communicable diseases plan or program, and about half (23/48) indicated having a section for PC in the national HIV plan or program. Forty-two percent indicated having a designated person, branch, unit, desk, or department within the Ministry of Health or equivalent government agency for PC, and 25% indicated having PC in the national budget.

Medicines. Nurse prescribing of opioids was reported in eight countries, of which the majority were in eastern Africa. The mean opioid consumption across all participating countries was 1.1 mg/capita/year, excluding methadone, and the median was 0.14 mg/capita/year, excluding methadone. Of the 11 countries that had >1mg/capita/year of consumption, distribution was more even across the UN geographical regions, with 3 countries in northern Africa, 3 countries in eastern Africa, 3 countries in southern Africa, and 1 country each in central and western Africa.
Still, the three countries with the highest consumption were from southern Africa (South Africa, Namibia, and Swaziland).

**Education.** Palliative care education is concentrated in western, eastern, and southern Africa. Of the 15 countries that have at least one medical, or 14 countries with at least one nursing, school with a PC course as a mandatory portion of the curricula, none are in central or northern Africa. Twenty-five countries reported having a national association for PC, of which 20 (80%) were in western, eastern, and southern Africa.

**PC Ranking**

Following the composite calculation, the top ten countries in terms of PC development were, in order, Uganda, South Africa, Kenya, Malawi, Tanzania, Cote D’Ivoire, Swaziland, Ghana, Rwanda, and Zimbabwe. (All of the values of the indicators are presented in Table 1 with a condensed summarizing of rankings by dimension in Table 2.)

In the PC specialized services domain, reflective of the overall ranking, Uganda, South Africa, Nigeria, and Kenya performed the best. In the policies domain, Botswana was ranked the highest, followed by Ethiopia, Rwanda, and Swaziland in second place; in medicines, Swaziland was ranked highest followed by South Africa then Malawi; and in education, Uganda and Kenya were ranked highest, then Zambia and Ghana in second place.

Of note, though certain countries ranked highly overall, when analyzed by dimensions, there were significant weaknesses in at least one dimension. For example, though Cote d’Ivoire was sixth in overall rankings, it was ranked 22\textsuperscript{nd} in the number of specialized services and, similarly, Zambia was tenth in overall rankings but 28\textsuperscript{th} in medicines, and Swaziland seventh in overall rankings but 24\textsuperscript{th} in education.

Also, only three countries (Uganda, South Africa, and Kenya) scored greater than 0.50 for their composite scores, showing a disparity between the top performing countries and the rest of the countries in Africa. Furthermore, even among the highest scoring three countries, there were substantial weaknesses in at least one dimension (e.g. PC policies for South Africa and Kenya).

**Discussion**

This is the first ranking of national PC development specifically for African countries. There are other global reports, as mentioned, measuring national PC development, but they either report on general development categories or cover very few African countries\textsuperscript{(4, 6)}. Our report, in contrast, ranks national PC development of 48 out of 54 African countries and, therefore, is the most comprehensive comparative analysis of how African countries fare compared to one another.
Comparing our ranking to these previous reports, there is a strong degree of congruence. For example, the top two countries from our ranking, Uganda and South Africa, are also listed as among the most developed countries in terms of PC development in both the Quality of Death Index(6) and the global atlas(4). In our report, Uganda performed the highest out of all African countries, followed by South Africa. The global atlas, similarly, placed Uganda in the highest category (level 4b) followed by South Africa (level 4a)(4), whereas the Quality of Death Index places South Africa above Uganda, but with an extremely small difference in overall relative scores(6). However, comparisons with the Quality of Death Index is limited because it only reports on 13 African countries, and comparisons with the global atlas are limited because it only provides qualitative categories whereas our information provides a ranking.

Here, we wish to add a cautionary word in interpreting the results, as well as listing some data limitations. Firstly, a ranking is only as good as the data obtained. The data, though cross-checked thoroughly with both the literature and experts at the APCA, is still self-reported by our experts, which included those working in the government or advocates, which creates risk for over-reporting across the various dimensions measured. Furthermore, due to the scarcity of African data and limitations in our methodology, some estimates may under- or over-estimate the reality of PC development that is simply not well-measured in African countries. However, for this reason, we believe that our data is the best available, to date, and therefore, still makes a significant contribution to the current literature. We tried to put other checks in place in order to try to verify the data received, including, but not limited to, cross-checking data with literature where available, cross-checking data with the African Palliative Care Association, and where possible, using two informants per country and reconciling with the two informants when there was divergent information.

In addition, when designing the survey for our key informants, we had to balance between gathering as much data as possible with gaining accurate data and gaining any data at all. If the estimates for the survey data are too difficult to answer, this created barriers to receiving responses. Therefore, some of our indicators are dichotomous variables (yes/no), and this creates a greater difference among countries where there is little overall national PC development as well as bias towards countries with a bigger population, such as in the education indicators. We tried to account for this by weighting indicators within each dimension. However, once again, we felt a ranking would be a stronger contribution to the literature since a general categorization system already exists in the global atlas, and a ranking, even with certain limitations, provides a clear view of where countries are in comparison to one another. We felt this is important for advocacy purposes as well as contributing to a better understanding of the comparative state of PC development in Africa.

Lastly, we would like to draw attention to the indicator of total number of PC specialized services, as this indicator, being the only indicator under the dimension of PC services, carries a significant weight in the final ranking. We chose to use total number of services rather than per population for a number of reasons. In countries where the number of services is so small (one
service, for example), by normalizing that variable per population, it created an artificial
differentiation between countries that did not reflect the reality of PC service delivery on the
ground. Furthermore, after running the rankings with services per population and reviewing our
results with experts, we felt it also did not reflect the realities of what is known on the ground in
terms of how developed various countries were in terms of PC, and that the absolute number was
a better indicator in terms of expert opinion as well as when compared with other global reports
on PC development. Therefore, we used the total number of PC specialized services, normalizing
it to the country with the highest number of total services.

One interesting aspects of our analysis was that not one country ranked first, or even
among the top three, in each of the WHO dimensions. This shows that, despite the fact that, for
example, Uganda, South Africa, and Kenya were the three highest performing countries in terms
of national PC development, there remain dimensions that are weaker for each country. The
breakdown of rankings by dimension in this current study highlights where even high-
performing African countries can focus their efforts to further PC development.

Another interesting aspect is that we found a Spearman correlation (r) of total hospice
and PC services with the GDP per capita showed no significant correlation (p=0.26), and the r
with health expenditure per capita also similarly showed no significant correlation (p=0.11),
indicating that the data could not prove the existence of correlation between the number of total
PC services and wealth or health expenditure of a country. When categorizing countries by
United Nations’ regions, southern and eastern African contain 86% of total HPC services on the
continent, despite having only 38% of the total population of participating African countries.

We believe this ranking is an important contribution to the literature because there is
limited data on how African countries fare in PC development relative to each other. This data
can be used as a reference point for future development and also provides additional information
as to which WHO dimensions individual countries need to work on. Furthermore, this paper uses
African-specific indicators that were suggested and rated by experts in palliative care in Africa,
providing a more context-specific comparison of palliative care specific to Africa. The data from
this manuscript were obtained from the APCA Atlas of PC in Africa(11), which is the first book
reporting quantitatively national PC development in the majority of countries in Africa.

Future directions include studying, in greater depth, each WHO public health strategy for
palliative care dimensions(15) and considering whether the dimensions themselves accurately
reflect the reality of PC development in Africa. For example, the dimensions do not account for
capacity building, one of the categories in the global atlas(4), and which reflects an important
aspect of progress in various countries in Africa that would better differentiate the state of one
country’s development compared to that of another. Other articles have similarly advocated for
additional dimensions, such as research, when speaking about PC development specifically in
Africa(17, 18). Future iterations of this research also include improving data gathering by
partnering with international organizations, like the WHO, to standardize who is responsible for reporting on this data at the country level, and therefore, allow for less variability in estimates.

**Conclusion**

Uganda, South Africa, and Kenya are the highest performing countries in terms of national PC development and were the only countries that scored a composite score of greater than 0.5 (50%). However, there is greater variability in rankings within each of the WHO dimension. This indicates that not one country universally supersedes all other countries in PC across all WHO dimensions, reflecting areas for improvement for each country.

**Competing Interests:** The authors declare no competing financial interests.

**Data statement:** Data may be obtained by emailing the first author. Most of the data used for this manuscript was obtained from a publicly available source: the *APCA Atlas of Palliative Care in Africa*.

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Bibliography


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Table 1. Summary of All Indicators Used in African PC Development Rankings

<p>| Mali         | 0.00 | 30 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 50 | 0 | 0 | 0 | 0 | 29 | 1 | 1 | 0 | 0 | 0.003 | 12 | 25 |
| Mauritania   | 0.01 | 23 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 38 | 0 | 0 | 0 | 0 | 29 | 0 | 0 | 0 | 0 | 0.001 | 33 | 45 |
| Mauritius    | 0.01 | 22 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 16 | 0 | 1 | 0 | 0 | 24 | 1 | 0 | 0 | 0 | 0.399 | 20 | 25 |
| Morocco      | 0.02 | 18 | 0 | 1 | 0 | 0 | 0 | 0 | 4 | 23 | 1 | 1 | 0 | 1 | 5 | 1 | 1 | 0 | 0.063 | 9 | 10 |
| Mozambique   | 0.01 | 12 | 1 | 0 | 0 | 0 | 0 | 0 | 6 | 21 | 1 | 0 | 0 | 0 | 20 | 0 | 0 | 0 | 0.056 | 32 | 30 |
| Namibia      | 0.01 | 22 | 0 | 1 | 1 | 0 | 0 | 1 | 6 | 15 | 1 | 1 | 0 | 0 | 10 | 1 | 1 | 0 | 0.017 | 6 | 14 |
| Niger        | 0.01 | 22 | 0 | 0 | 0 | 0 | 0 | 0 | 6 | 38 | 1 | 0 | 0 | 0 | 20 | 1 | 1 | 0 | 0.005 | 12 | 26 |
| Nigeria      | 0.07 | 6 | 0 | 1 | 1 | 0 | 0 | 0 | 1 | 46 | 1 | 1 | 0 | 1 | 5 | 1 | 0 | 0 | 0.002 | 25 | 15 |
| Republic of Congo | 0.00 | 38 | 0 | 0 | 0 | 0 | 0 | 0 | 20 | 0 | 0 | 0 | 0 | 29 | 0 | 0 | 0 | 0.008 | 23 | 30 |
| Rwanda       | 0.02 | 15 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 0 | 0 | 10 | 1 | 1 | 0 | 0.023 | 11 | 8 |
| São Tomé &amp; Príncipe | 0.00 | 38 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 39 | 0 | 0 | 0 | 0 | 29 | 1 | 0 | 0 | 0.079 | 28 | 36 |
| Senegal      | 0.02 | 15 | 0 | 1 | 0 | 0 | 1 | 0 | 4 | 20 | 0 | 0 | 0 | 0 | 29 | 1 | 0 | 0 | 0.011 | 23 | 26 |
| Sierra Leone | 0.02 | 15 | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 25 | 0 | 0 | 0 | 0 | 29 | 0 | 1 | 1 | 0.002 | 18 | 26 |
| South Africa | 0.76 | 2 | 1 | 0 | 1 | 1 | 1 | 4 | 19 | 1 | 0 | 1 | 1 | 5 | 1 | 1 | 0 | 1.000 | 2 | 2 |
| South Sudan  | 0.00 | 35 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 38 | 0 | 0 | 0 | 0 | 29 | 0 | 0 | 0 | 0.000 | 33 | 45 |
| Sudan        | 0.02 | 15 | 0 | 1 | 0 | 0 | 0 | 0 | 6 | 28 | 0 | 0 | 0 | 0 | 29 | 1 | 0 | 0 | 0.006 | 23 | 32 |
| Southland    | 0.16 | 6 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 2 | 0 | 0 | 0 | 24 | 1 | 1 | 1 | 0.790 | 1 | 7 |
| Tanzania     | 0.07 | 6 | 1 | 1 | 1 | 0 | 1 | 0 | 1 | 39 | 1 | 1 | 0 | 0 | 10 | 1 | 1 | 1 | 0.013 | 5 | 5 |
| Togo         | 0.00 | 32 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 28 | 0 | 0 | 0 | 0 | 29 | 0 | 0 | 0 | 0.008 | 33 | 38 |
| Tunisia      | 0.01 | 22 | 0 | 1 | 1 | 0 | 1 | 1 | 1 | 16 | 0 | 0 | 0 | 0 | 29 | 0 | 1 | 0 | 0.390 | 21 | 26 |
| Uganda       | 1.00 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 5 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0.057 | 4 | 1 |
| Zambia       | 0.16 | 6 | 0 | 1 | 1 | 1 | 1 | 0 | 4 | 12 | 1 | 1 | 1 | 0 | 3 | 0 | 1 | 0 | 0.069 | 28 | 10 |
| Zimbabue     | 0.09 | 9 | 1 | 1 | 1 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 10 | 1 | 0 | 1 | 0.012 | 17 | 18 |</p>
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Table 2. Condensed View of African PC Rankings by WHO Dimensions
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Figure 1. Weighting of Dimensions and Indicators in the Calculation of PC Development Rankings for African Countries.

**Palliative Care Development**

- **PC Specialized Services (35.6%)**
  - Normalized total hospice and palliative care services (100%)
- **PC Policies (13.8%)**
  - Budget/Funding (15%)
  - Stand-alone policy (15%)
  - HIV policy (14%)
  - Cancer Policy (13%)
  - Desk/Trend (13%)
  - Clinical guidelines (13%)
  - National PC Association (14%)
- **Medicines (25%)**
  - Oral morphine availability (29%)
  - Consumption of oral morphine (25%)
  - Prescribing laws/regulations (24%)
  - Nurse prescribing (22%)
- **PC Education (25.6%)**
  - Education in Medical schools (38%)
  - Education in Nursing schools (25%)
  - Existence of specialization (25%)
  - National PC Conference (22%)