

Nurses' engagement in AIDS policy development

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Background: A multidisciplinary team of 20 researchers and research users from six countries – Canada, Jamaica, Barbados, Kenya, Uganda and South Africa – are collaborating on a 5-year (2007–12) program of research and capacity building project. This program of research situates nurses as leaders in building capacity and promotes collaborative action with other health professionals and decision-makers to improve health systems for human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) nursing care. One of the projects within this program of research focused on the influence of workplace policies on nursing care for individuals and families living with HIV. Nurses are at the forefront of HIV prevention and AIDS care in these countries but have limited involvement in related policy decisions and development. In this paper, we present findings related to the barriers and facilitators for nurses' engagement in policymaking.

Methods: A participatory action research design guided the program of research. Purposive sampling was used to recruit 51 nurses (unit managers, clinic and healthcare managers, and senior nurse officers) for interviews.

Findings: Participants expressed the urgent need to develop policies related to AIDS care. The need to raise awareness and to 'protect' not only the workers but also the patients were critical reason to develop policies. Nurses in all of the participating countries commented on their lack of involvement in policy development. Lack of communication from the top down and lack of information sharing were mentioned as barriers to participation in policy development. Resources were often not available to implement the policy requirement. Strong support from the management team is necessary to facilitate nurses involvement in policy development.

Conclusions: The findings of this study clearly express the need for nurses and all other stakeholders to mobilize nurses' involvement in policy development. Long-term and sustained actions are needed to address gaps on the education, research and practice level.

Keywords: AIDS, Barriers, Canada, Facilitators, Jamaica, Kenya, Nurses, Policy Development, South Africa, Uganda

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Background

'You just find something that is ready to be eaten but you are not involved in cooking it.'

Uganda participant quote on their involvement in policy development

The demands of existing and upcoming health challenges to address the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) pandemic globally require innovative policy responses, and not merely just more evidence. We are living in an era of rapid change and clear and concise policies are essential to interdisciplinary approaches to population health and to address major pandemics, such as HIV (Cheung et al. 2011). Numerous recommendations from international and regional bodies (PAHO 2004) urge the inclusion of nurses as participants in policy development at all levels of the health system. Nurses are ideally situated to understand and recognize the policy determinants of health as they deliver the majority of frontline care and are well connected with patients and the environment (Reutter & Duncan 2002).

A variety of economic, social and political issues necessitate the nursing professions' involvement in policy development. Nurses play a leading role in healthcare delivery and are responsible for a major portion of care provided to those living with HIV and AIDS including educating the population (Davey 2004; Simbayi et al. 2005). It is essential that nurses participate in policy development that affects their day-to-day work with AIDS patients. Although nurses are generally well prepared educationally and play leadership roles within clinical, educational, research and administrative domains, their contribution to the health policy process has been constrained by a lack of research training and mentoring, limited access to research funding, limited experience with effective knowledge transfer strategies, and few opportunities for dialogue with policymakers (Edwards et al. 2009).

A multidisciplinary team of 20 researchers and research users from six countries – Canada, Jamaica, Barbados¹, Kenya, Uganda and South Africa – are collaborating on a 5-year (2007–12) program of research and capacity building project (Edwards & Roelofs 2007). Sub-Saharan Africa and the Caribbean are the two regions of the world with the highest HIV prevalence rates. Nurses are at the forefront of HIV prevention and AIDS care in these countries but have limited involvement in related policy decisions and development.

Purpose

This program of research situates nurses as leaders in building capacity and promotes collaborative action with other health professionals and decision-makers to improve health systems for HIV and AIDS nursing care (Edwards & Roelofs 2007). One of the projects within this program of research focused on the influence of workplace policies on nursing care for individuals

and families living with HIV. In this paper, we present findings related to the barriers and facilitators for nurse engagement in policy development and implementation.

Methodology

A participatory action research design guided the program of research, which included four interrelated projects. Ethical approval for the study was obtained from the research ethics board at the University of Ottawa (site of principal investigator) and from 15 research ethics boards in each of the partner countries and Canada where the co-investigators are located.

Fifteen qualitative and quantitative research instruments, including interviews, focus groups, surveys and document analysis, were used in the four projects. Purposive sampling was used to recruit unit, clinic and healthcare managers, and senior nurse officers from each of the institutions who had participated in the completion of the Human Resource Management rapid assessment tool (Management Sciences for Health 2003). Interviews were conducted to explore the influence of workplace policies on the ability of nurses to provide care for individuals and families living with HIV and to access treatment for themselves. Following informed consent, the interviews were conducted in English by a research assistant in each of the study countries, using guiding questions to ensure the topic of interest was explored in a similar way with each participant. In the current paper, we report on findings from 51 interviews (J = Jamaica, 10; K = Kenya, 17; U = Uganda, 12; SA = South Africa, 12) with nurses. Interviewed participants are identified with an 'I'.

Data analysis

All of the interviews were transcribed verbatim and research team members collaborated through regular data analysis meetings to conduct a thematic analysis of the data. This approach is also compatible with the NVivo8 (QSR International 2008) qualitative software that was used to code (i.e. label), categorize, classify, store and manage the data for this project (Boyatzis 1998). During the data analysis process, an experienced qualitative researcher (SR) worked with less experienced researchers in each of the study countries. The transcribed interviews were co-analysed by research assistants and co-investigators in each country and an experienced researcher to ensure rigor and enhance capacity building in the country teams.

Findings

The need for AIDS policy: 'For the protection of workers'

Participants expressed the urgent need to develop policies related to AIDS care. The reality of working in an environment where

¹One year after program funding was received, Barbados withdrew from the program of research.

nurses care for a large number of AIDS patients contributed to this urgent need. A Kenyan nurse believed that: 'the number has increased, increased gradually up to around 1000 at the moment so we had to come up with policies whereby we spread [out] the number of clients per week.'

The needs to raise awareness and to 'protect' not only the workers but also the patients were critical reasons to develop policies that influenced their day-to-day nursing practice. A Jamaican nurse remarked: '... more persons were coming in testing positive, and so we have to prepare our staff to be aware, so that the staff can protect themselves, but also the clients and other persons that are coming into the facility' (JI#5). Participants reflected on the need to establish policies on discrimination to protect everyone involved in the caregiving. A South African nurse recommended that the focus of the policies should be on developing guidelines 'to ensure that there is no discrimination of anybody' (SAI#1). Workplace policies were needed to ensure that all staff was protected from infection and to ensure that they continued to take care of AIDS patients. 'Also getting infected at a workplace is a hazard. It would give a bad picture to the rest of the staff, they would start fearing to treat the patients most especially those with HIV and then that would lead to neglect of those people with HIV' (UI#2).

Policies were also necessary to address the inconsistencies in caring for HIV-positive patients. Well-developed policies contributed to the standardization of practices and had a legal purpose. A Kenyan nurse provided rationale for the development of policy: '... standardization of the practice because we have to work within the standards at national level ... and for legal purposes because if you do not have a legal policy document that allows you to operate in a certain way you may not be working as per what is required' (KI#3).

Nurses' involvement in policy development: 'No you are not allowed to develop policies'

Nurses in all of the participating countries commented on their lack of involvement in policy development. They were either not allowed to participate in policy development or policies were imposed from the top down. A Jamaican nurse said: 'No, you are not allowed as a health center to [participate in] policy development' (JI#5). Nurses stated that their primary role was to implement policies without participating in their development. When asked whether the organization participated in policy development at the facility level, a Kenyan nurse noted, 'we actually use the policies that have been forwarded to us from the ministry of health headquarters' (KI#9). A South African nurse had a similar perspective: 'It's mostly the national one's that we really use in our own organization' (SA#11). Nurses were also not knowledgeable about the policy development process. Another

nurse stated: '... I don't know what it entails or what is required to start making a policy' (KI#15).

Participating nurses were concerned about their lack of involvement in the policy development process, adding that they were 'not consulted on the ground because they actually should be asking us ... how it [policy] affects our service' (KI#11). Nurses described their involvement in the policymaking process as 'indirect involvement' and stated that they had to communicate their views through those in positions of authority. A Jamaican nurse reflected: 'No, we don't have any direct input in policy. ... when we have our monthly meetings, we express our feelings. ... She [manager] has direct [contact] with the policy makers. ... So we hope when we go to her she will help to enact it' (JI#16). The policymaking process was described as politicized and top down in nature. As one nurse stated: 'Policy making on HIV and AIDS is mostly down loaded to us' (KI#19). Another nurse believed that nurses had a voice but said: '... that many of these things are political so even if you want to bring about change, it becomes difficult if you are not politically inclined' (SAI#3).

When asked if nurses had an opportunity to influence government policy, some participants expressed a desire to be involved but lamented the lack of opportunity to influence policy. One nurse stated: 'We would have loved to have that [political] influence but it is not possible' (UI#20). Participants clearly express the need for nurses and all other stakeholders to mobilize nurses' involvement in policy development and to be represented at the government level. A nurse believed that she '... can only see this happen if the nurses are represented on top' (UI#8).

Barriers to implementing policy

Lack of communication and sharing of policies: '... unfortunately they have not been put up in different areas ...'

Nurses at the grassroots level were not well informed about the existence of policies. A Kenyan nurse summed it up: 'It is that we don't have the policies here on the ground level at this organization' (KI#5). An Ugandan nurse believed that lack of communication from top managers to workers contributed to policies not being implemented: 'You see at times these workshops they only pick the area managers. ... they teach them things and they come and at the end of the day they don't communicate to the staff ...' (UI#11). Other participants commented that information was often not well circulated, documented, or accessible, or publicly displayed. An Ugandan nurse shared that: '... [policies are] not written anywhere because people are just taking these things to be light' (UI#10). Another Ugandan nurse reflected on the availability of policies: 'We have them in books but unfortunately they have not been put up in different areas where one can read and find them' (UI#2).

Insufficient resources: 'You improvise and use what you have'

Heavy patient workloads, a shortage of staff and insufficient time prohibited nurses from updating themselves on the latest policy changes: '... the number of [HIV] clients is increased so much. The uptake of ARV's is also increasing and patient care ... holistic care is also increasing and on the negative side still because of the shortage of staff. We have been actually again over strained by the services' (KI#11). Resource allocation to implement policies was a reason why policies were not adequately implemented. Participants were frustrated when policies on universal precautions were posted and available, but lack of resources prevented them from adhering to the policy. The lack of space for counseling, privacy, supplies to handle waste, sufficient drugs and 'overstrained workers' constrained nurses' ability to implement policies and guidelines and affected overall care of patients. 'Some policies are there but they aren't being implemented ... they say each hospital setting should have protective gears but we definitely find that we are going without them ...' (UI#12).

An Ugandan nurse stated that guidelines were available but the lack of involvement of management was making the implementation difficult: 'There are some guidelines which are there, ... but at times they are not followed because of that and when you look at the top managers they don't care they say you improvise and use what you have ...' (UI#9).

Facilitators to nurses' involvement in policy development: '... we give them the feedback ...'

Bottom-up approach

Nurses suggested that they be consulted on issues related to their workplace to ensure participation in the policy development process. Frontline nurses and managers participated in the policymaking process when they were consulted: 'Persons were invited to a workshop. ... We sat in groups and suggested what we think ought to be in this policy and then we worked from there' (JI#1).

A nurse from Kenya suggested a 'bottom up approach whereby those who are developing the policies came down on the ground [to meet with those] who are providing the services [to] look at the gaps – the challenges we are having' (KI#14). Mechanisms to ensure that nurses' feedback reached the policy decision-makers at the national level were recommended: '... we are the practicing nurses and we know what we go through so in these meetings we give them the feedback and the feedback is taken up to the people at the national level who are laying down the guidelines for any amendments' (UI#1). National policies were important but frontline nurses needed to 'give it a local flavor' to fit their context. Policies were usually filtered down to the organizational level through national and international guidelines. They men-

tioned that local workplace policies are guided by and built on the national policies. A Jamaican nurse said: '... we're using the national policy as a guide and you modify it to suit the region' (JI#1).

Management support: 'They cascade the information down'

Participants recommended a strategic plan and management system to ensure that the policies were in place and followed. Participants agreed that managers played an important role to ensure that policies were appropriately implemented and supervised. Leadership and guidance from nursing management helped within the implementation process and to keep staff informed. They also ensured that policies were monitored and revised if needed. A South African nurse manager believed that: '... they [frontline staff] are not actively involved in policy making but they are informed, trained and they [nurse managers] cascade the information down and see that the policies are implemented. Our major role is monitoring if the policy is well implemented, if there are any obstacles regarding the policy which needs to be revised ...' (SA#4).

Human resource support: '... we have to be giving risk allowance ...'

Participating nurses mentioned that policies that provided moral support for HIV-positive nurses who fear job instability were essential. It would contribute to and assist with creating a positive workforce. Nurses requested some leniency in their duties: 'I want to believe that if such a policy could be there then there should be no discrimination for those [nurses] who are HIV positive so that there should be some consideration for them' (KI#14). Compensation in the form of incentives was mentioned as a form of motivation to care for AIDS patients. Incentives should include risk allowance and other forms of compensation (allocated sick days) during the period of post-exposure prophylaxis use: 'some allowance during the period that you are taking PEP because even the side effects are not so pleasant so you might absent yourself from duty' (KI#1).

Discussion

Our participants shared many barriers that prevented them from participating in policy development and implementation, but also mentioned facilitators that promoted involvement. Nurses are the primary link between the various governance systems and the clinical setting and a vital link to ensure effective HIV and AIDS care (Milstead 2004). A strategy that nurses utilize to facilitate involvement in HIV and AIDS policy formulation includes the policy feedback loop. The policy feedback loop gives nurses 'hands on' experience on how to communicate policy problems or gaps to managers and how to lobby policymakers to ensure that this feedback is used to adapt policies and contribute to

balancing the top-down policy approach (Heywood 2002; Shamian et al. 2006). Literature support partnership approaches to assist and support bottom-up approaches to policy development. It allows access to information and resources and translates research rapidly into policy and practice (Pawinski & Lalloo 2006).

Participants in our study described various barriers to nurse participation in policy development including individual and organizational capacities. The dual pandemic of HIV and tuberculosis (TB) coincides with a health workforce shortage necessitate the urgent need for nurses to be involved in HIV policy development and specific policies to protect healthcare workers (WHO-ILO-UNAIDS 2010).

There are different approaches that can be used to formulate HIV and AIDS policies: the top-down, bottom-up or the in-between approach (WHO 2006). In all our participating countries the top-down approach was used with regard to policy formulation and implementation. Generally, participants did not participate in policy development. They were mainly involved in the implementation of policies. Local needs were often overlooked (Ngulube 2005). HIV policies were developed at the national level of government and implementation was often very methodical allowing limited feedback from the frontline nurses who were expected to implement the practices associated with the policy. It is well known that within a top-down approach it is common for policies to be implemented and evaluated by government according to specific objectives as set out during the formulation of the policy (Cloete et al. 2000). Nurses experienced the top-down approach as negative because they were absent from the policy table and merely seen as policy implementers. Involvement of nurses at all levels of policy formulation can be of value to ensure the sustainability of HIV and AIDS workplace policy (Zellnick & O'Donnell 2005). Our participants believed that they were primarily implementing policies that were developed at the national level. This phenomenon has been described previously by several authors (Marchal et al. 2005; UNAIDS 2003; WHO 2006). Nurses' involvement in the HIV policy process has largely been relegated to that of implementation despite being the largest group of frontline workers with a 24/7 presence in the global healthcare delivery system. A 'top-down' approach to nurses' involvement in HIV policy is largely a function of limited opportunities for access and contributions to the health policy process. Greater involvement of nurses is required to influence policy decisions for better and improved care to persons with HIV and AIDS. Nurses are at the forefront of dealing with the HIV epidemic and HIV has had a dramatic impact on the nursing profession.

Our participants experienced a lack of communication with management level staff. Olivier & Dykeman (2003) recommend

that lobbying with managers is especially important to address program deficiencies and policy gaps. Frontline nurses are well situated to identify policy gaps during the implementation of HIV and AIDS policies and can suggest remedial steps, which can contribute to a bottom-up policy approach. Implementing, practicing and expanding the bottom-up approach to develop HIV workplace policies will eventually balance the top-down policy formulation approach. The performance of districts/regions/provinces bottom-up actions regarding the formulation and implementation of HIV and AIDS policies will in the long run have a ripple effect, and thus improve the image of the districts and of frontline nurses (Mechanic & Reinhard 2002). Gilson et al. (2006) explored the role of policy in promoting equity in healthcare services and highlighted that frontline nurses seldom provided feedback or advice to higher authorities or had the opportunity to be involved in policy development. Their main role was to ensure compliance and implementation of these policies. If they did not comply, they were perceived as difficult and a misfit in the health institution.

Gilson and colleagues (2006) argued that a lack of trust between management and frontline nurses contributed and threatened the effective formulation and implementation of policies. Frontline nurses were often not consulted prior to the implementation of a new policy and it was assumed that they should willingly agree to implement it. Nurses were not given the opportunity to provide feedback on how the policy impacted them (Gilson et al. 2006). The participants in our study had similar remarks and said that policies were often not shared or publicly displayed.

Resource allocation and a shortage of resources were stated as a reason why policies are not implemented. The World Health Organization (WHO) recommends partnerships between donors, governments, and non-governmental and local organizations to ensure that frontline healthcare workers receive sufficient resources. Long-term investment is needed to ensure collaboration and healthcare financing to support comprehensive health policy development and care strategies (Kitahata et al. 2002). Nurses believed that heavy workload influenced their ability to participate in policy development. Zellnick & O'Donnell (2005) stated that more patients are being diagnosed with HIV and caring for AIDS patients requires more intensive and sometimes prolonged care. This places more demands on nurses within a global era of a shrinking healthcare workforce. Furthermore, the top-down policy process is experienced by nurses as bureaucratic authority (Gilson et al. 2006; Zellnick & O'Donnell 2005).

Human resource support, and more specifically salary improvement, was emphasized by our participants as an incentive to participate in policy development. The lack of adequate recognition and remuneration was extensively discussed during

the ICN conference in Durban, SA (Leading Change: Building Healthier Nations 2009). Dominance by the medical establishment, submissiveness of nurses who fail to speak up in the public sphere, and minimal acknowledgement of nurses' contributions to the management of the HIV epidemic are also contributing factors to the lack of involvement in policy development (Phaladze 2003).

The International Council of Nurses (2005) state that nurses can make a major contribution in shaping health policy. Nurses closely interact with healthcare consumers in a wide variety of settings. Nurses have a broad appreciation of health needs, including how factors in the environment affect the health situation for clients and their families.

Implications for policy and practice

Focusing nursing research on priority areas in the policy agenda is important. A fundamental component of nurse's contribution to policy development should include participation in sharing of research results that serve as a sound basis for decision-making and the allocation of resources (Shamian et al. 2006). Long-term and continued actions are needed to address gaps on the education, research and practice level. Nurse leaders worldwide should take an active participatory decision-making approach when it comes to policy development related to their practice. Education of nurses should include an emphasis on policy development with strong emphasis on their advocacy role.

Study limitation

We only collected data with participants who have full command of the English language. It was not the first language for many participants but all nurses and midwives would have been eligible based on language. English is the official working language and/or one of the official working languages in each of the study countries.

Conclusion

Nurses in all the participating countries commented on their lack of involvement in policy development. It is mainly related to a lack of communication and information sharing. Resources were often not available to implement the policy requirements. Strong support from the nursing management team is necessary to facilitate nurses' involvement in policy development. The findings of this study clearly express the need for nurses and all other stakeholders to mobilize nurses' involvement in policy development.

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Conflict of interest

There is no conflict of interest.

Author contributions

SR: Study conceptualization, data analysis, drafting the manuscript and critical revisions for important intellectual content. JM: Study conceptualization, data analysis and critical revisions for important intellectual content. RM: Data analysis and drafting the manuscript. EK: Study conceptualization, data analysis and critical revisions for important intellectual content. JE: Study conceptualization and drafting the manuscript. PD: Data analysis and drafting the manuscript. CH: Data analysis.

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