

# **Original Article**

# Results of an Integrative Analysis: A Call for Contextualizing HIV and AIDS Clinical Practice Guidelines to Support **Evidence-Based Practice**

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#### ABSTRACT

Keywords

HIV and AIDS nursing care, clinical practice guidelines, best practice guidelines, care delivery, lower- and middle-income countries, context. adaptation, nurses and midwives

Background: Practice guidelines aim to improve the standard of care for people living with HIV/AIDS. Successfully implementing guidelines requires tailoring them to populations served and to social and organizational influences on care.

Aims: To examine dimensions of context, which nurses and midwives described as having a significant impact on their care of patients living with HIV/AIDS in Kenya, Uganda, South Africa, and Jamaica and to determine whether HIV/AIDS guidelines include adaptations congruent with these dimensions of context.

Methods: Two sets of data were used. The first came from a qualitative study. In-depth interviews were conducted with purposively selected nurses, midwives, and nurse managers from 21 districts in four study countries. A coding framework was iteratively developed and themes inductively identified. Context dimensions were derived from these themes. A second data set of published guidelines for HIV/AIDS care was then assembled. Guidelines were identified through Google and PubMed searches. Using a deductive integrative analysis approach, text related to context dimensions was extracted from guidelines and categorized into problem and strategy statements.

Results: Ninety-six individuals participated in qualitative interviews. Four discrete dimensions of context were identified: health workforce adequacy, workplace exposure risk, workplace consequences for nurses living with HIV/AIDS, and the intersection of work and family life. Guidelines most often acknowledged health human resource constraints and presented mitigation strategies to offset them, and least often discussed workplace consequences and the intersections of family and work life.

Linking Evidence to Action: Guidelines should more consistently acknowledge diverse implementation contexts, propose how recommendations can be adapted to these realities, and suggest what role frontline healthcare providers have in realizing the structural changes necessary for healthier work environments and better patient care. Guideline recommendations should include more explicit advice on adapting their recommendations to different care conditions.

## BACKGROUND

Many guidelines have been developed to control the spread and reduce the impact of HIV on communities and healthcare providers (Kredo et al., 2012; National Institutes for Health and Care Excellence, 2011). As nurses comprise the largest segment of the workforce in HIV/AIDS care delivery in lowerand middle-income countries (LMICs; Turale, 2016), guidelines with recommendations for this cadre of health workers are particularly important.

Despite the development of many HIV/AIDS guidelines, their uptake has been inadequate and uneven (Granato et al., 2016; Nuwagaba-Biribonwoha et al., 2015). At state levels,

reasons for this poor uptake have been attributed to insufficient healthcare financing and supply-line failures (Blacklock et al., 2016), restrictive health professional regulations regarding scope of practice (McCarthy et al., 2013), and punitive legislation on homosexuality and illicit drug use (Church et al., 2015; Gruskin et al., 2013). At local levels, barriers to implementation include lack of knowledge about guidelines; and negative attitudes toward implementation resulting from concerns about costs and supplies, excessive demands on healthcare providers, and the cultural inappropriateness of recommendations including gender considerations (Aizire et al., 2013; Blacklock et al., 2016; Gourlay et al., 2013; Granato et al., 2016; Karim

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et al., 2011; Mwai et al., 2013; Schuster et al., 2016; Shayo et al., 2014).

Thus, there is increasing recognition that guidelines need to be tailored not only to populations served but also to health workers and the social, organizational, and environmental barriers they encounter in providing care (Harrison et al., 2010; Mugala et al., 2010; Mwai et al., 2013; Schuster et al., 2016). Contextualizing guidelines is expected to improve their uptake, as recommendations would be more feasible to implement.

Substantial attempts have been made to advance processes for contextualizing clinical practice guidelines. Earlier efforts that documented barriers to guideline implementation resulted in frameworks that help characterize inner and outer contextual influences on guideline implementation (Cane et al., 2012; Damschroder et al., 2009; Dopson, 2007; Greenhalgh et al., 2004). Recent work has focused on empirical studies of processes for guideline adaptation (Fervers et al., 2011). Developing an approach that is systematic, yet efficient and timely has proven challenging (Harrison et al., 2013).

#### AIMS

This study examined the perspectives of nurses from four LMICs about the salient dimensions of context that influenced their provision of HIV/AIDS care. An analysis of HIV/AIDS guidelines determined whether or not they included adaptations congruent with these dimensions of context. Recommendations for improving the contextual adaptation of HIV/AIDS guidelines are provided.

### METHODS

Two sets of data were used for this analysis. The first came from a qualitative study undertaken as part of a research program (Edwards et al., 2016) to strengthen HIV/AIDS care by nurses in Kenya, Uganda, South Africa, and Jamaica. The second data set was assembled using published clinical practice guidelines.

### Qualitative Study of HIV/AIDS Care by Nurses

The original qualitative study examined nurses' and midwives' experiences of how the HIV/AIDS epidemic had affected their workforce and their provision of services in the four study countries. Ethics approval was obtained from the University of Ottawa and from each of the ethics review boards in participating countries (Edwards et al., 2016). Informed consent was obtained from each participant.

**Data collection and sampling.** In-depth interviews were conducted by trained research assistants. Registered and enrolled staff nurses and midwives, and nurse managers, were purposively selected from randomly sampled healthcare institutions in 21 study districts/parishes. (In Jamaica, parishes are the equivalent of districts. The term districts rather than districts/parishes will be used throughout the remainder of this paper.) Details of district and institutional sampling are provided elsewhere (Edwards et al., 2016). Participants were chosen based on the advice of senior district health authorities who directed researchers to those who were working in HIV/AIDS care and knowledgeable about its impact on the workforce. Eligible nurses and midwives (hereafter referred to as nurses) had been employed at the institution for at least 3 months. Interviews were conducted from 2008 to 2009. For the purposes of this paper, only responses to the first interview question and related probes were used for analysis. The question asked was "How has the HIV/AIDS epidemic affected the nursing and midwifery workforce in your district/parish?" We probed for positive and negative effects on workforce supply, retention and recruitment; working conditions including workload; and nursing leadership.

Analysis of qualitative interviews. Interviews were audiotaped, and transcribed verbatim. The NVivo 8 (QSR International, 2008) software was used to manage data. Data were content analyzed using an inductive approach (Elo & Kyngäs, 2008). A coding framework was developed iteratively. All transcripts were initially coded by a trained research assistant and the coding framework reviewed by team members. Five emergent themes were identified. We reexamined these themes and related subthemes to identify the contextual drivers of HIV/AIDS care. Four context dimensions emerged. Data for these four dimensions were then compared using a matrix to explore their relevance to all study countries.

### Clinical Practice Guidelines

Search strategy and inclusion criteria for selecting guidelines: Clinical practice guidelines were initially identified in 2015 by conducting Google searches (see Table SI) to identify study country-, region-, and LMIC-specific guidelines. One hundred and thirty web pages were reviewed. In 2016, terms used in Google searches were applied in a PubMed search. Guidelines from both searches were retrieved, assessed for eligibility (see Table S2), and duplicates removed. We then hand-searched the reference lists of included guidelines to identify additional guidelines. In total, 28 guidelines were retained following these steps (see Figure S1). Our dual (Google and PubMed) search strategy identified a larger set of guidelines than a PubMed search would have done alone.

Inclusion criteria for content review of guidelines: We then developed inclusion criteria to identify content pertinent to nursing practice, using the International Council of Nurses' definition of the same (2002). These criteria were used to determine which chapters or segments of guidelines to screen for content (see Table S2). We applied these criteria to the table of contents of all eligible guidelines. This resulted in five additional guidelines being removed, as they did not contain content meeting these criteria.

We reviewed the entire text for nine guidelines and segments of text for 14 guidelines. Text that was definitely or marginally related to any of our four context dimensions was extracted in its entirety by KH. NE reviewed a subset of these guidelines to confirm that all relevant text had been identified. We cross-checked findings using a key word text search.

Analysis of extracted text: Using a deductive analysis approach, guideline text identified for each context dimension was grouped into the categories of problem statements about the context and mitigation strategies to address the problem. Subcategories were then identified and compared for the four dimensions of context. During this rereading of the extracted text, those found to be irrelevant to the context dimensions was discarded from final analysis.

### RESULTS

#### Demographic Characteristics of Participants From Qualitative Interviews

Ninety-six nurses completed qualitative interviews (see Table S<sub>3</sub>). The majority of participants were female staff nurses, educated at the certificate or diploma level, who worked in district health centers.

#### Qualitative Interviews—Context Dimensions

Four discrete dimensions of context emerged: health workforce adequacy, workplace exposure risk, consequences for nurses living with HIV and AIDS, and intersections of work and family life. Each of these context dimensions was described by at least some participants from all study countries. However, there were intercountry variations in both the nature of and the emphasis placed on these dimensions by respondents.

Health workforce adequacy. Workforce adequacy concerned both the quantity of workers and their preparedness and capacity to care for HIV patients. Respondents spoke about the chronic shortage of nurses and the increased numbers of persons living with HIV and AIDS, many of whom sought health care in late stages of the disease when they required intensive nursing care. Increased workloads adversely affected the standards of care. A nurse manager explained: "We have so many patients in hospitals who are suffering from HIV/AIDS and other opportunistic infections ... the work has been so great and the nurses are few; therefore, they cannot adequately cater for the patients" (K-10, Nurse Manager). Although the shortage of nurses was common to all participating countries, contributing factors differed. Participants in Kenya and Uganda identified HIV infections and deaths among nurses alongside migration as key factors. A Ugandan nurse stated "Many nurses and midwives have died on the job. We get infected in the process of working and treating the patients" (U-15, Frontline Nurse).

Nurses in the three African countries spoke of nursing shortages explaining that they were the combined result of high turnover and structural adjustment policies, which meant that departing nurses could not be replaced. A Kenyan nurse stated: "the government has really abandoned the inflow [of employed nurses]" (K-II, Frontline Nurse). Respondents in South Africa also identified poor remuneration and heavy workloads as issues. In Jamaica, the chronic shortage was mainly attributed

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to nurses migrating to higher-income countries for better pay because they were dissatisfied with poor work environments.

**Workplace exposure risk.** The risk of occupational injury and exposure to HIV infection was described as a major concern in Kenya, Uganda, and Jamaica and to a lesser extent in South Africa. Several nurses reported being injured while caring for patients. Some became infected with HIV because they did not have access to resources for protection or postexposure prophylaxis.

We lack instruments and all the necessary protective gears like aprons, gloves, boots etc. We now tell patients to buy for themselves. ... We do prick ourselves while injecting the patients and end up getting infected in the process. We don't have 'PEP' [postexposure prophylaxis] at [this] health center. (U-IO, Nurse Manager)

Participants from Kenya, Uganda, and Jamaica attributed occupational exposure to HIV to a lack of basic supplies and physical infrastructure (e.g., running water), which impeded the implementation of universal precautions. "We have problems with equipment and supplies, and there are times when we run out of gloves. We still don't have enough equipment to protect us from HIV" (J-5, Frontline Nurse).

In addition, nurses from Kenya and Jamaica described the inability of healthcare institutions to handle large numbers of HIV-infected patients requiring complex care, and the lack of resources to provide appropriate care. A nurse from Kenya remarked: "We still have the constraints ... shortage of commodities, lack of space for privacy and also our in-patient bed capacity for the HIV clients is really taking a bit of a toll on us" (K-13, Nurse Manager).

Workplace consequences for nurses living with HIV and AIDS. In contrast to the experiences of nurses in Jamaica, stigma and discrimination related to HIV infection was a major concern of nurses in the other countries. Nurses with HIV and AIDS from Uganda and Kenya reported fear of stigma and discrimination from their colleagues. One of the Kenyan nurses stated "especially those who are HIV positive there is some sort of discrimination by their fellow colleagues" (K-2, Frontline Nurse). A Ugandan nurse expressed her concern that nurses living with HIV/AIDS were excluded from training opportunities. "If [nurses] are to go for further training, it is mandatory for them to go for HIV/AIDS testing and if they are found positive, they lose that chance" (U-16, Frontline Nurse).

Some HIV positive nurses did not disclose their HIV status and for that reason did not get the required treatment. "You find that some [nurses] fear to disclose ... they die quickly without being assisted" (U-4, Frontline Nurse).

South African nurses who were known to work with individuals living with HIV and AIDS were described as being stigmatized by their community. A South African nurse reflected: "the community ... has this perception that the nurses who

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are working with HIV positive patients are also HIV positive" (SA-16, Frontline Nurse).

**Intersecting work, family, and home life.** Some nurses experienced tension at home related to fear their family members had of contracting HIV. This was particularly apparent among South African nurses. Participants also described how their increased workloads and stressful work environments impacted their families. Some of them expressed that they were not able to fully attend to their families' needs due to physical exhaustion. Some nurses suggested that the challenges of their HIV/AIDS work had contributed to the break up and disorganization of families. Several nurses lamented,

You get home [and] cannot care for your family now. You are exhausted from the duties; when children come to you, your attitude changes, you become angry; you're a non-caring mother because of the existing work condition. (SA-12, Frontline Nurse) [HIV]... has also made even some of the families of the nurse break because the spouse thinks maybe it's a nurse who brought the infection [home] as she takes care of HIV positive patients. (K-6, Nurse Manager)

#### Characteristics of Guidelines

Of the 23 guidelines reviewed (see Table S4), 18 (78.3%) had been prepared for healthcare providers. Fifteen (65.2%) guidelines targeted policy makers, program managers, or other stakeholders; six (26.1%) guidelines were country-specific (Uganda, Kenya, and South Africa); and two (8.7%) were regional. Seven (30.4%) guidelines had been developed for target populations. Some guidelines covered the continuum of care from prevention to treatment, whereas others addressed a specific facet of care. Table S5 summarizes the instances of text extracted during the review of context dimensions and from the keyword search.

## Context Dimensions in Practice Guidelines: Integrative Results

For all context dimensions, two types of descriptors were apparent: problem statements and strategies to address the problem (see Table S6). Problem statements identified the issue as a contextual consideration for guideline implementation, using descriptors such as the magnitude or nature of the problem and its consequences. Some guidelines addressed these contextual challenge(s) from the patient perspective, whereas others addressed them from the perspective of the formal or informal healthcare provider. These differing perspectives were pertinent for two context dimensions: occupational exposure (risks to patients vs. professionals), and intersecting family and work life (formal health providers vs. informal care providers). For the workplace consequences for HIV positive healthcare providers as patients versus as care providers.

Strategy descriptions were statements of how to address the contextual challenges. For the dimension of health workforce

adequacy, strategies were grouped into those specifically targeting the health workforce versus those addressing related issues such as healthcare financing. For the dimensions of exposure risk and consequences, strategies were grouped into behavioral approaches and/or local workplace policies versus policies, regulations or laws at the state level. Finally, for the intersecting work and family life dimension, strategies were categorized into those for formal healthcare providers and those for other caregivers.

Overall, across all dimensions, health human resource constraints were most often acknowledged and those for which the largest proportion of mitigation strategies were identified. Workplace consequences for nurses living with HIV/AIDS and the intersections of family and work life were dimensions least often identified.

**Dimension of health workforce adequacy.** Among the 20 (87%) guidelines that addressed health workforce adequacy, some emphasized staff constraints such as inadequate numbers or insufficient training, whereas others presented a broader set of financial and material health system constraints. The most consistent mitigation strategy proposed was training. Other measures included recruiting more staff, developing new cadres of health workers, improving coordination and planning, developing new partnerships to optimize resources available, task shifting, and improving supportive supervision.

Strategies aimed at financial and material resource constraints included decentralizing services, linking and integrating HIV and other care services, and deploying strategies to retain staff and maintain a healthy workforce. One guideline described approaches that could be used to assess workforce adequacy and distribution. Only two guidelines addressed the need for changes in laws and regulations to authorize different personnel to distribute antiretrovirals or carry out HIV testing and counseling.

**Dimension of occupational exposure.** HIV exposure risk for patients or providers was addressed in 12 (53.1%) guidelines. Exposure risk for sex workers was highlighted in several guidelines. In others, the risk of patients being exposed when a health provider was HIV positive was discussed. Only five guidelines mentioned needle stick injuries; some guidelines contained recommendations related to postexposure prophylaxis.

Mitigation strategies were primarily those at the institution level, with mentions in six (26.1%) guidelines. State-level regulations and laws to protect the worker and reduce the risk of workplace exposure were mentioned in only two (8.7%) guidelines.

**Dimension of workplace consequences.** Eight (34.8%) guidelines discussed consequences for health providers living with HIV or providing care for HIV positive patients. The most common consequences identified for both groups were stigma and discrimination. Accessing confidential health services and managing financial repercussions such as lost wages were challenges identified for HIV positive health workers.

Mitigation strategies were identified in only five (21.7%) guidelines. These strategies included making adjustments in the workplace for employees who are HIV positive; providing confidential services for testing and treatment; helping to alleviate stigma through training and information-sharing; and ensuring that workers' rights are respected.

**Dimension of intersecting work**. *Family and home life*: Eight (34.8%) guidelines addressed intersections of work, family, and home life for formal or informal care providers. Consequences identified primarily had to do with the potential risks of disclosing occupationally acquired HIV such as stigma, violence, abandonment, or harassment. The clearest examples of intersecting work, family, and home life identified in guidelines were the anxiety worker's families and partners had about the risk of HIV transmission, the emotional and financial hardship for family members when a healthcare worker became HIV positive, and caregiver burden challenges. No guidelines directly addressed the dual burden of caring for HIV patients in the workplace and being an informal caregiver for a person living with HIV/AIDS at home.

The discussion of strategies for this dimension was sparse. Examples included using family-centered approaches, assessing an HIV-infected woman's social and emotional support system, addressing the emotional impact and financial hardships that may follow an HIV diagnosis, and ensuring affordable treatment for spouses or dependents. There were no structural intervention strategies identified.

**Concluding result.** With the exception of health workforce adequacy, there were few mentions of the other three contextual dimensions in guidelines, in the form of problem statements or mitigating strategies. Some contextual realities identified by nurses during interviews, such as the dual burden of caring for HIV patients in the workplace and at home, received no mention in guidelines.

#### DISCUSSION

Unlike many previous studies on barriers, our interviews with nurses elicited their experiences of the HIV/AIDS epidemic in their community and workplace. This yielded some important insights, particularly about the intersections of work and family life. The context dimensions nurses identified highlight the multiple ecologies that influence HIV/AIDS care provision (Gruskin et al., 2013; Schuster et al., 2016). While reinforcing the need for contextualizing guidelines, they also point to the complexity of doing so. All four context dimensions were pertinent to each country; between-country differences primarily reflected the timing and trajectory of the epidemic and the varying responses of governments to the epidemic.

During qualitative interviews, nurses identified many instances when they faced ethical dilemmas related to their role as HIV care providers. Professionally, they wanted to provide quality care, but were sometimes unable to do so due to workplace constraints. In delivering care under these circumstances, they had to make difficult choices that put them or their patients at risk. These choices impinged directly on their family lives, creating further internal conflict. Gruskin et al. (2013) described similar dilemmas, observing that changes in mesoand macroenvironments are needed to help health workers deal with ethical challenges encountered in providing care. However, guidelines provided few mitigation strategies directly related to these challenges.

Our findings highlight the incongruences between guideline content and nurses' experiences of providing HIV/AIDS care and suggest two critical considerations in the contextual adaptation of guidelines. First, an exclusive focus on barriers to implementing guidelines for patients fails to acknowledge the intersection of workplace, social, and family realities on providers of care. Social and family influences on the care givers' experience, may directly affect their workplace morale and stress, retention in the workplace, and risk of occupational injuries. These influences need to be addressed in all guidelines, not just those with a primary focus on the health provider.

Second, concrete guideline recommendations related to institutional policies or state-level regulations and laws were uneven and sparse for all context dimensions, despite evidence that these kinds of structural changes are prerequisite to improvements in clinical care (Barker et al., 2015; Gruskin et al., 2013; Horwood et al., 2015; Youngleson et al., 2010). We recommend that messages about the importance of these policy and regulatory changes be included in future guidelines to help advance structural improvements. Statements reinforcing the role of nurses in advocating for policy improvements may buttress their efforts to improve workplace policies that can safeguard both themselves and their patients.

Guidelines will have no influence on practice unless they are accessible. In LMICs, guideline recommendations are often translated into practice-oriented tools such as clinical algorithms as a means of improving their accessibility. Accompanying directives and training on the use of these algorithms provide an opportunity to embed specific guidance for adaptation and to discuss the ethical challenges health workers face as they attempt to provide good care under conditions of contextual adversity. Quality improvement approaches also show considerable promise as a means to incorporate guideline recommendations in ways that strengthen a "bottoms-up" and practitioner-informed approach to guideline adaptation (Barker et al., 2015; Edwards & Barker, 2014; Horwood et al., 2015).

# CONCLUSIONS

Guidelines help set benchmarks for better care. To avoid having guidelines dismissed because they are considered irrelevant to the challenges of nursing care provision in LMICs, more guidance on the adaptation of recommendations to different care conditions is needed. All guidelines need to not only acknowledge the different contextual parameters at play, but also propose how recommendations can be adapted to these realities, and how frontline healthcare providers can be supported in addressing the structural changes needed for healthier work environments and better patient care. **WVN** 

# LINKING EVIDENCE TO ACTION

- Clinical practice guidelines should include more specific directions on the adaptation of recommendations to different contexts for providing care.
- Guidelines need to more consistently acknowledge diverse implementation contexts and propose how recommendations can be adapted to these realities.
- Guidelines should highlight what role nurses have in realizing the structural changes necessary for healthier work environments and better patient care.

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# SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's web site:

Table S1. Guideline Search Details

Table S2. Criteria for Guideline Inclusion and Content Review

Table S3. Demographic Characteristics of Nurses Participating in Qualitative Interviews

Table S4. Guideline Reference List

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**Table S5.** Total Instances of Text Occurrences in Guidelines From Reviews Based on Context Dimensions and Keyword Searches**Table S6.** Results of Guideline Text Extraction for Context Dimensions: Text Occurrences Grouped by Problem Statement andStrategy Descriptions

Figure S1. Overview of selection and review process of guidelines.