Chapter six

Optimizing chronic HIV care in the Dutch Caribbean: an in-depth questionnaire based study on experience and perception of health care workers

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Chapter 6

Abstract

Human Immunodeficiency virus (HIV) infection has increasingly become a chronic disorder for which adaptation of current health care practices is needed. In Curaçao, presently a new organization of chronic HIV care is being set up based on task shifting, in which health care workers (HCWs) will deliver HIV care more prominently within the primary health care system. In preparation for implementation of the proposed task-shifting model we investigated the perception of HCWs regarding existing HIV care in Curaçao and the need for training in HIV/AIDS among HCWs. An in-depth questionnaire based study was used. Nineteen HCWs of 7 different cadres were interviewed. The questionnaire constituted 4 sections: quality of existing HIV care, respondents own knowledge and willingness to be trained, need for training in HIV/AIDS and preferred educational approaches. Quality of existing HIV services in Curaçao is considered acceptable but needs improvement mainly to facilitate integration of chronic HIV care. All respondents indicated that training in HIV/AIDS is needed among HCWs in Curaçao, especially for nurses and GPs. All were willing to participate in training with varying amount of time willing to be spent. Training should be tailored to the level of expertise of HCWs and to the role a HCW is expected to have in the new health care delivery framework. There is need for training to ensure the effective integration of chronic HIV care in the existing health care delivery system in Curaçao with e-learning as a preferred educational tool.
Introduction

One of the major constraints in improving the management of human immunodeficiency virus (HIV) care is the limited human resource availability. To combat this lack of human resources the World Health Organization (WHO) developed an interim guideline based on task shifting, aimed at facilitating the rapid scaling-up of antiretroviral therapy (cART) in resource constrained settings and integrating HIV care in primary health care (PHC) delivery systems. Task shifting is defined as a process of delegation whereby tasks are appropriately moved to health care workers (HCWs) with lower qualification requiring specific training. A similar task shifting approach seems recommendable in order to better accommodate chronic HIV care in existing treatment programs.

In the pre-cART era in small Caribbean settings like Curaçao, acute HIV care could satisfactorily be managed by a few health care providers. However, as HIV infection is becoming a chronic disorder, an integrated management approach is needed within PHC. Curaçao is a Dutch Caribbean island with approximately 140,000 inhabitants and an estimated HIV infection prevalence of 0.61%-1.05%. Care for HIV infected patients (including cART provision) is provided by a single physician at the St Elisabeth Hospital. A recent report on cART efficacy in Curaçao showed late clinical presentations, high rates of lost to follow-up and a low virological response in HIV-1 infected individuals. In order to integrate HIV care into the current PHC delivery system of Curaçao, task shifting to different cadres of health care providers should seriously be considered.

To effectively prepare for the implementation of a task-shifting model we therefore decided to examine the perception and experience of HCWs regarding the current status in Curaçao of HIV care and concomitant training needs.

Methods

Provider roles in task-shifting model

Task shifting requires the transfer of specific clinical responsibilities to other HCWs who need to be trained for the tasks. In our case, task shifting was aimed at integrating HIV care into the PHC delivery system, involving the participation of several cadres in HIV care. A potential model for Curaçao was developed by the authors and is shown in Figure 1.
**Figure 1:** Current model of HIV care in Curaçao and the task shifting model that shows integrating chronic HIV care into the primary health care delivery system. (Based on *Chronic HIV care with ARV Therapy and Prevention: Integrated Management of Adolescent and Adult Illness Guideline, WHO 2007*).

<table>
<thead>
<tr>
<th>Current</th>
<th>Task-shifting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Specialists</strong></td>
</tr>
<tr>
<td></td>
<td><strong>General Practitioners</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Nurses/ other HCWs</strong></td>
</tr>
</tbody>
</table>

- Develop treatment plan
- Initial cART prescription in patients with complications
- Supervise clinical team(s) at first level
- Toxicity management
- Evaluate for treatment failure
- Manage severe illness and malnutrition
- Clinical monitoring
- HIV clinical staging
- Check TB status
- Check pregnancy
- Assessment of cART eligibility
- Treat opportunistic infections
- Therapy adherence preparation and support
- Respond to new signs and symptoms
- Referral to specialist in case of complications, toxicity or treatment failure
- cART prescription refills
- Arrange follow-up
- Start chronic care including education, support and prophylaxis
- Prevention interventions: basic prevention and positive prevention
- Suspect HIV, test and counsel

**Legend Figure 1:** cART, anti-retroviral therapy; HIV, human immunodeficiency virus; TB, Tuberculosis; HCWs, Health care workers.

**In-depth questionnaire**

To effectively prepare for the implementation of the proposed task-shifting model a qualitative study was conducted among HCWs to whom certain tasks would be delegated. An in-depth questionnaire was designed by the authors and used to investigate the perception and experience of HCWs regarding the existing HIV care and their training needs.

The questionnaire consisted of 4 sections. In the first section, respondents were asked to rate quality of existing HIV care (on a Likert scale from 1 to 10) and to explain their rating. The second section included questions about respondents’ knowledge and training needs and their attitude towards their task in HIV care. In the third section respondents were asked to rate the need for training of 6 different cadres of HCWs involved in HIV services in Curaçao.
using a Likert scale (1 not necessary; 5 very necessary). Total scores were taken to define the cadres that mostly needed training in HIV/AIDS. Medians and ranges were calculated to define respectively overall scores and the consensus per cadre. In the last section they were asked to define the most appropriate educational approaches and topics for training in HIV/AIDS.

The interviews were semi-structured i.e. the conversations were guided with pre-defined questions that needed to be asked. (Appendix 1) During the interview 2 interviewers literally wrote down answers. The analysis took place in a cyclic process wherein per item established themes and text parts were coded and described. These codes and described text parts were categorized according to their similarities. Relations were established after discussion by the educationalist and the researcher (J.B. and H.H. respectively).

Results

Baseline characteristics of respondents

Nineteen HCWs of 7 different cadres were interviewed individually Table 1 shows baseline characteristics of the respondents. Six respondents were already involved in daily HIV care, of which 3 provided prevention services through NGOs, 1 HCW provided cART, 1 distributed cART and 1 was responsible for policy making. Only 1 GP reported not being involved in HIV care at all considering HIV care to be specialized care.

Section 1: Quality of existing HIV care

The respondents rated the quality of HIV care in Curaçao with a median of 7.0 (interquartile range [IQR], 5.8–7.5). (Table 1) Two respondents indicated that HIV care could be improved, but did not know how. The respondent who gave a score of 2.5 provided several reasons: a lack of collaboration between/within different HCW groups involved in HIV care, non-sustainability of current HIV care with only 1 provider, lack of central coordination, and poor access to cART for the uninsured or undocumented immigrants due to high costs. (Table 2)

Section 2: Respondents’ knowledge and willingness to be trained

All interviewees indicated a need for personal training in HIV/AIDS with time willing to be spent ranging from 2 hours per year to unlimited (with respondents currently more involved in HIV care willing to spend more time than those less involved). The main reasons for their training need included: knowledge update (N=5), lack of information on specific topics related to their area of expertise (N=4), very dynamic nature of the disease (N=2) and ‘never know enough’ (N=2). Rated on a scale from 1-10, the interviewees rated their personal knowledge with a median of 6.3 (IQR, 6.0 – 7.0). (Table 1)
Table 1: Baseline characteristics of respondents who participated in the survey.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>37%</td>
</tr>
<tr>
<td>Involvement in HIV care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>6</td>
<td>32%</td>
</tr>
<tr>
<td>Frequently</td>
<td>3</td>
<td>16%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>8</td>
<td>42%</td>
</tr>
<tr>
<td>Never</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Cadre</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>4</td>
<td>21%</td>
</tr>
<tr>
<td>NGOs</td>
<td>3</td>
<td>16%</td>
</tr>
<tr>
<td>Specialist</td>
<td>4</td>
<td>21%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>GPs</td>
<td>4</td>
<td>21%</td>
</tr>
<tr>
<td>PER</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>PD</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Knowledge of HIV/ aids (median, IQR)</td>
<td>6.3</td>
<td>6-7</td>
</tr>
<tr>
<td>Own quality of HIV services (median, IQR)</td>
<td>7</td>
<td>6.8-8</td>
</tr>
<tr>
<td>Quality of HIV services (median, IQR)</td>
<td>7</td>
<td>5.8-7.5</td>
</tr>
</tbody>
</table>

Legend Table 1: NU, nurses; NGO, non-governmental organizations; SP, specialists; Ph, pharmacists; GP, general practitioners; PER, physician at emergency department; PD, policy maker Public Health Department; UK, unknown.

Table 2: Suggestions given by interviewees to improve the quality of HIV care in Curaçao.

<table>
<thead>
<tr>
<th>Suggestions to improve HIV care in Curaçao</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integration of HIV care</td>
<td>4</td>
</tr>
<tr>
<td>Increase information for the general population</td>
<td>4</td>
</tr>
<tr>
<td>Central coordination of HIV care</td>
<td>3</td>
</tr>
<tr>
<td>Updating knowledge among HCWs and population</td>
<td>3</td>
</tr>
<tr>
<td>Improving access to cART, cost reduction and provision of free access to undocumented immigrants</td>
<td>3</td>
</tr>
<tr>
<td>Do not know how</td>
<td>2</td>
</tr>
<tr>
<td>Decrease discrimination and stigma, not further specified</td>
<td>2</td>
</tr>
<tr>
<td>Better collaboration between different cadres</td>
<td>2</td>
</tr>
<tr>
<td>Surveillance, active follow-up of PLWH</td>
<td>1</td>
</tr>
<tr>
<td>More prominent role of public health in coordination</td>
<td>1</td>
</tr>
<tr>
<td>Increase education in HIV among physicians</td>
<td>1</td>
</tr>
<tr>
<td>More political involvement</td>
<td>1</td>
</tr>
<tr>
<td>Patient centered care focusing on adherence</td>
<td>1</td>
</tr>
<tr>
<td>Specialized HIV nurse</td>
<td>1</td>
</tr>
<tr>
<td>Increase research, a current lack of data</td>
<td>1</td>
</tr>
<tr>
<td>Centralized clinic for HIV care with specialized nurses</td>
<td>1</td>
</tr>
</tbody>
</table>

Legend Table 2: HIV, human immunodeficiency virus; HCWs, Health care workers; cART, anti-retroviral therapy; PLWH, people living with HIV.
Section 3: HIV training for different cadres

All respondents indicated that training in HIV/AIDS is necessary among HCWs in Curaçao. The main reason given was that knowledge of HIV care among HCWs was not up to date (N=5) and that general knowledge of HIV/AIDS was lacking at every level of health care (N=3). Another reason indicated by interviewees (N=5) was the necessity to change from current centralized HIV care (1 treating physician) towards integration into PHC because of better sustainability (N=2) and quality of chronic care (N=3) was required (i.e. early detection of side effects and non-compliance). Three interviewees responded that education among HCWs in Curaçao was needed to change the attitude of HCWs towards PLWH and to address stigma and discrimination. Eleven respondents indicated that training is necessary for their own cadre. Two interviewees responded that next to their own cadre, every cadre in the health care sector needs training in HIV/AIDS. Six respondents indicated that other cadres had a higher need for training than their own cadre, namely PHC workers (N=3) and nurses/personnel of nursing homes (N=3).

All interviewees were asked to score the necessity of HIV training for 6 cadres to whom certain tasks would be delegated according to the proposed task shifting model (GPs, medical specialists, NGOs, nurses, laboratory personnel, and pharmacists). All cadres scored a median of 5 (out of 5), except for laboratory personnel (median= 4). The highest total score with the smallest range was given to nurses and GPs (total 87 (range= 4-5) and 84 (3-5) respectively) compared to medical specialists, pharmacists, laboratory personnel and NGO personnel (total 82 (range= 2-5), 78 (2-5), 76 (2-5) and 76 (1-5) respectively). The main reason that was given for scoring nurses and GPs as the most important group in need of training was because of their ‘daily and direct involvement in HIV care’. Remarkably, 3 GPs did not judge themselves as the most important group for getting training as they indicated to have no role in current HIV care at all.

Other cadres of HCWs in need of HIV training not mentioned in the questionnaire but proposed by the interviewees were social workers (N=5), visiting nurses (N=4), midwives (N=3), ambulance personnel (N=2), psychologists (N=2), dentists (N=2), public health workers (N=2), dieticians (N=1), paramedical personnel (N=1), physical therapists (N=1), hospital personnel (N=1), and emergency department personnel (N=1).

Apart from professionals in the health care sector, the interviewees indicated that the general population (N=6), school teachers (N=4), police department (N=2), family and friends of PLWH (N=1), the fire-brigade (N=1), barber or hair stylists (N=1), insurance companies (N=1) and media (N=1) needed HIV training. The main reasons given were: to decrease discrimination and stigmatization of PLWH and to better inform persons in order to prevent HIV infection.
Section 4: Educational approaches and topics

According to the interviewees the topics for HIV/AIDS training depend on the expertise or cadre of the HCW with most important topics being antiretroviral therapy, side effects and interaction of cART (N=10), prevention of HIV infection (N=7), general knowledge of HIV/AIDS (N=7) and training in social and attitude aspects (N=3).

The preferred learning methods were: e-learning (N=5), a conference (N=4), an interactive course (N=3), combined e-learning with interactive courses (N=3), conferences combined with interactive courses (N=2), an exchange program combined with interactive courses (N=1) and all kind of methods (N=1). One interviewee mentioned that a central organization should be responsible for training and quality control of the knowledge of HCWs providing HIV services to prevent involvement/participation of unqualified personnel. There was no relationship observed between the preferred learning method and the expertise or the level of involvement in HIV care of the interviewee.

Discussion

In contrast to developing countries (especially Sub Saharan Africa) where, because of severe shortage of HCWs, task shifting is used to rapidly scale up access to HIV care and treatment\textsuperscript{1-7}, Curaçao needs task shifting to integrate HIV care into PHC in order to better address the increasing chronic nature of the disease, improve the quality and optimize the efficacy of cART.\textsuperscript{8} Therefore it seemed important to examine the perception and attitude of HCWs on HIV care.

The study had 4 major findings: training in HIV is perceived to be necessary among HCWs in Curaçao, there is a willingness of HCWs to participate in training, training in HIV should be tailored to the level of expertise of HCWs and quality of existing HIV services is considered acceptable but needs improvement mostly by integration into PHC and in communication among HCWs. This is, to our knowledge, one of the first studies describing the perspective of HCWs towards training and task shifting in HIV care.

Albeit critics have urged caution about maintaining quality of care when shifting tasks to lower cadres, there is growing evidence of maintained or even improved quality outcome when shifting tasks to PHC especially in early diagnosis and care retention.\textsuperscript{7,14}

Although individual willingness of all interviewees to participate in training was observed, few indicated their own cadres not to have the highest training priority. Our findings show that training seems most needed for nurses and GPs as those cadres are involved in daily care of PLWH and have through the years been delegated with increasing responsibilities in...
HIV care supporting existing literature. Remarkably in our study, GPs did not identify their cadre as the most important to be trained in HIV care. Mainly because they felt that they had little or no responsibilities in HIV care compared to other cadres of HCWs. Bodenheimer et al. already reported that the chronic care model constitutes a major rethinking of primary care practice. Therefore, this rethinking is essential when planning for task shifting. Task shifting can only be effective if all roles and responsibilities are clearly defined and accepted, including tasks for community health workers, family members and patients.

Our results also indicate that training aimed to implement task shifting should be tailored to the level of expertise, the level of involvement and the tasks of HCWs in current and future HIV care programs as also suggested by others. An earlier report showed that training in HIV/AIDS in Curaçao that is aimed in part to increase efficacy of cART should at least be targeted towards the early identification and rapid referral of PLWH. In addition, it should also aim to improve adherence and compliance to therapy and retention of care. Interestingly, e-learning was considered a valuable training tool by most participants. The promising results obtained in several developing countries with e-learning programs support the potential positive impact of such an educational approach.

Only a few studies, limited to specific areas of HIV care, have been published on task shifting in the Caribbean. Muhkerjee et al. showed the successful effect of task shifting by involving community HCWs in providing medical therapy and emotional support to PLWH in Haiti. In this study, the role of HCWs in the delivery of HIV care was to identify vulnerable groups and facilitate use of PHC services. Another study described how nursing interventions formed a key feature in the ongoing development and success of a prevention of mother-to-child HIV transmission program in Jamaica with a strong necessity for continuous education and training. No information on the HCWs’ initial perspectives and attitudes and how this influenced the task shifting design was reported.

When shifting some clinical responsibilities to nurses, GPs and other HCWs, we must consider the modified role of the medical specialist, who will provide care for patients with complications and at the same time support and guidance of patient management by others. As proposed by one of the interviewees a national committee should be responsible for monitoring and evaluating the level of knowledge and skills of HCWs working in HIV care to assure quality of care. In addition, a comprehensive training program for initial and continuous education should be developed as part of a national HIV/AIDS management plan. Furthermore, standardized protocols, adapted medical records and tools to assist HCWs to perform HIV care are pivotal in implementing task shifting and achieving the proposed goals. Given the current organization of HIV care with the availability of only 1 expert for care and treatment in Curaçao, pure task shifting without strengthening the current HIV care program will not be feasible and investment in human capital is required.
A limitation of this study could be the response recording, which was written rather than audiotaped. However text phrases were literally written down to prevent interpretation. Also, the selection of interviewees was based on HCWs currently presumably involved in HIV care and cadres of HCWs involved in the proposed task-shifting model. Although not included, studies on (relatives of) PLWH’ perspectives will also be of importance, especially because of the importance of patient self-management in chronic care management. Constant critical analysis of successful, sustainable and cost-effective implementation models remains of importance.19

Acknowledgements
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Appendix 1: Guidance of pre-defined topics to be asked during the semi-structured interviews.

Involvement in HIV care
Need for training in HIV/AIDS among HCWs in Curaçao:
- NGOs
- Specialists
- General Practitioners
- Nurses
- Laboratory personell
- Pharmacy personell
- Other HCWs
- None HCWs

Topics of training in HIV/AIDS
Method of training in HIV/AIDS
Personal need for training
Time willing to invest
Improvement quality of HIV care in Curaçao
Rating:
- Personal knowledge of HIV/AIDS
- Personal quality of HIV care
- Quality of HIV care in Curaçao

Legend Appendix 1: HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome; NGOs, non-governmental organizations; HCWs, health care workers.
References
