

Does the provision of services for HIV positive patients, including the provision of antiretroviral therapy, meet the needs and expectations of employers in Knysna?

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Declaration

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Abstract

In South Africa, the highest HIV prevalence is amongst young people, who may have the greatest potential to contribute to the country's economy.

South Africa has one of the world's largest antiretroviral (ARV) rollout programs. Like all medications, ARVs need to be taken as prescribed to be safe and effective. Excellent adherence is necessary to ensure that drug resistance does not develop. HIV cannot be cured, and at present ARVs must be taken for the rest of the patient's life.

In the ARV clinic in Knysna, an unanticipated category of patients has been identified: those who "bounce" in and out of long term therapy. Not only do these patients put their own health at risk, but the development and transmission of drug resistant HIV threatens the potential treatment options of the whole community.

One of the problems identified in recurrently defaulting patients, is the difficulty in maintaining long term adherence to an ARV treatment program, while in full time employment.

This is because as time goes on, patients need to balance the need for ARV care, which has rigorous clinic attendance parameters, with work attendance. Many employees have only twelve days of paid sick leave per annum, and patients require an average of eleven clinic visits in the first six months of treatment.

This qualitative study gauges whether the services provided to HIV positive people living in Knysna meets the needs of their employers.

The study interviewed both employees and employers to gauge the effects of HIV on local businesses, and explored the knowledge and attitudes of employers towards services provided by the Knysna ARV program.

Employers were asked to suggest ways in which the services could be improved to better meet their needs, and ultimately, the needs of their employees.

Options to improve access which emerged from the study include extending the opening hours of the ARV clinic, as many patients have working hours which directly correspond to the opening hours of the ARV clinic.

Tools need to be developed to deliver information about HIV disease and treatment to employers, as in general, knowledge about these aspects of HIV care is poor. Information on legislation governing HIV in the workplace should be included for employers and employees. Opportunities to be counseled and tested for HIV, at work, should be explored.

Improving communication between employers, employees and the providers of care was identified as a factor which may mitigate many of the problems associated with long term access to care.

It is imperative to find ways to integrate full time employment with effective HIV care and treatment programs to ensure their long term success.

Opsomming

Die hoogste HIV prevalensie in Suid Afrika is onder jong mense, wat ook moontlik die grootse potensiaal het om tot die ekonomiese toekoms van die land by te dra.

Suid Afrika het een van die grootste ARV-programme ter wêreld.

ARV's moet, ten einde veilig en doeltreffend te wees, soos voorgeskryf geneem word. Uitstekende insiklikheid met medikasie skedules is nodig om middelweerstandigheid te voorkom. HIV kan nie genees word nie en ARVs moet dus geneem word vir die res van die pasiënt se lewe.

In die ARV kliniek in Knysna is 'n onvoorspelde pasiënt kategorie geïdentifiseer, nl. die wat in en uit lang termyn behandeling "bons". Hierdie pasiënte plaas nie slegs hulle eie gesondheid onder risiko nie, maar die ontwikkeling en oordraagbaarheid van behandelingsweerstandige HIV bedreig ook die potensiële behandelingsopsies van die hele gemeenskap.

Een van die probleme wat geïdentifiseer is by pasiënte wat herhaaldelik afspraak mis, is dat langtermyn volhoubaarheid bemoeilik word deur voltydse indiensneming.

Met verloop van tyd moet pasiënte hulle nodigheid vir ARV behandeling, wat streng kliniek bywoning vereis, balanseer met 'n werkgewer wat soms toenemend vyandig raak.

Hierdie kwalitatiewe studie ondersoek of die dienste wat aan HIV positiewe pasiënte aangebied word in die Knysna area, voldoen aan die verwagtinge van werkgewers.

'n Aantal in-diepte onderhoude met werkgewers bepaal wat die effek van HIV op hulle besighede is, asook watter kennis en gesindhede hulle inneem teenoor die dienste wat deur die staatskliniek gelewer word.

Werkgewers is gevra om maniere voor te stel hoe die dienste verbeter kan word om aan hulle benodigdhede te voldoen. Dit behoort ook aan die benodigdhede van hul werkers te voldoen.

Opsies wat die toegang na die kliniek sal verbeter, sluit in: Om die openingsure van die kliniek te verleng, omdat baie pasiente se werkure direk ooreen stem met die werksure van die kliniek.

Systeme moet ontwikkel word om informasie oor HIV siekte en behandeling oor te dra aan werkgewers, want kennis van HIV sorg is swak. Informasie oor wetgewing wat HIV in die werksarea reguleer, moet ook ingesluit word. Geleenthede om vir HIV by die werk getoets te word, moet ontwikkel wees.

Beter kommunikasie tussen werkgewers en professionele dienste mag baie van die probleme van langtermyn toegang tot HIV sorg vir werkers oplos.

Dit is noodsaaklik dat maniere gevind word om voltydse HIV-positiewe werkers en effektiewe HIV behandelingsprogramme te integreer, om hul lang termyn gesondheid te verseker.

Table of contents

Declaration	0
Abstract	1
Opsomming	3
Abbreviations and Acronyms	7
Introduction	8
Literature review	10
Study Aim	14
Study Objectives	14
Study design	14
Study Population	15
Reliability	16
Methodology	17
Methods of analysis	19
Resources	20
Results of the interviews with employers	21
Discussion	24
Recommendations	26
Conclusion	26

Bibliography28

References31

Abbreviations and Acronyms

AIDS acquired immunodeficiency syndrome

ARV antiretroviral medicine

DOH Department of Health

HAART highly active antiretroviral therapy (triple drugs)

HIV human immunodeficiency virus

SME small/medium enterprises

TB tuberculosis

UN United Nations

VCT voluntary counseling and testing

WHO World Health Organization

Introduction

The researcher runs a busy ARV clinic at the Knysna Provincial Hospital, with 1135 patients on antiretroviral medication. About 20- 30 treatment naive patients are started on ARVs each month.

Far fewer men start on ARVs¹ than women, but once in the program, men and women have equal mortality rates, equal transfer out rates and equal defaulter rates. However, there is one unanticipated category where men are over represented, which our clinic calls “the bouncers”.

Serial defaulters complete the counselling process, and are assessed as suitable for the program. They are started on medication, and are adherent to their scheduled clinic visits for varying lengths of time. They then default treatment. After another variable interval, these patients return to the program, are very contrite, and request treatment again. They are reassessed, re-counselled, and restarted. They are adherent for varying lengths of time, until the process repeats itself.

Patients who serially default give many different reasons for this process, but all of them relate to the difficulty in accessing long term care.

As discussed, many of our serial defaulters are men. Men we have talked to, say they find it difficult to maintain long term adherence to the program, while maintaining full time employment.

This is because as time goes on, they need to balance the need for accessing care from an ARV programme which has rigid clinic attendance parameters, with employment commitments. Most employers get 12 days paid sick leave per annum,² and the average number of visits to the clinic required in the first six months is 11.

¹ The ratio of women to men starting the program is 61:39

² The Basic Conditions of Employment Act allows thirty six days per three year cycle. In practice, after employees exhaust their twelve days for the year, many employers are unwilling to grant further paid sick leave.

Obviously women also work, but more women have part time employment and most are able to fit visits around the days they do not work.

Conversely, while many employers are perceived to be hostile to employees who are continuously “sick”, employers in turn struggle to manage their staff and work schedules, with employees who are regularly absent from work.

This tension between access to health care and maintaining employment can cause short periods of regular attendance at the clinic, followed by intermittently poor adherence, and can cause multiple defaulting behaviours from employees.

Finding out what makes employers happy, could help us design a program that keeps employees/patients in care.

Literature review

The *Lancet*, in an editorial published last year, describes HIV/AIDS as a “global disaster” with a “catastrophic effect on the population, health systems, *economy* and social stability...of *Southern Africa*.” (1) (Emphasis mine)

Combining ARV treatment and work commitments is not a unique problem for South African patients.

A WHO report investigating adherence to ARVs in Botswana, Tanzania and Uganda states: “*Individuals trying to take all of their medicines are often trapped in a vicious circle of social, economic and workplace obstacles hampering their adherence to treatment*” (2) (emphasis mine), and;

“*reasons found for adherence failure were... work related problems such as not getting time off to go to the clinic or stigma in the workplace*” (2) (emphasis mine).

A literature review showed that most workplace based HIV programs concentrate on HIV education and provide emotional support for people living with HIV/AIDS. Most services are peer based.

South Africa is a world leader in the development of work based HIV/AIDS treatment programmes. Anglo American, specifically mentioned in the UN best practice series, realized that

“*even innovative and comprehensive (prevention) programs are not enough to stem the tide, if not coupled with effective treatment initiatives*” (3)

Their massive programs have had excellent results.

“...the provision of ARVs and other care and support mechanisms nearly doubles the capacity of people...to carry on working. There is no debate about costs/benefits”. (3)

Many other large South African private sector companies have also launched workplace HIV/AIDS treatment programs in the past three years. The manner in which this is provided is usually by one of the following models:

- Employer provided, where the employer internally finances and delivers treatment;
- via a medical scheme where the employer subsidises the premiums to employees who are prepared to make a co-payment;
- by a specialised HIV/AIDS disease management company or by a clinic provider – an external care provider provides care at an outside (private) clinic (4)

Very few companies have the resources or expertise to run in house programs. Drug manufacturers make HIV drugs available at reduced costs to national governments, but are unwilling to make these products available at similarly low costs to private sector providers in the same countries. This means that even if companies wish to run in house programs, the costs can be prohibitive.

Most companies offer to subsidize medical aid membership to employees and (sometimes) dependants. However, only a minority of employees can afford the co-payments, and membership is concentrated amongst managers and supervisors, who may be the least likely to be HIV positive. For less skilled workers, low uptake of program benefits, means program failure, wasted money, wasted time and wasted lives.

Private external care providers or disease management companies need to provide the quality of care required to maintain patients on cheaper first line regimens for long periods of time. However, they often are unwilling to pay for the expensive multidisciplinary team required to ensure long term adherence.

When the cheaper first line options are exhausted, patients are referred to State services for salvage regimes.

A series of articles in the Cape Times newspaper pointed out that in most South African companies, it is cheaper to treat than ignore HIV and it is financially worthwhile for a company to do so (5)

However, many smaller employers are implementing minimalist interventions in the mistaken belief that they are providing *some* HIV services, while still managing to save money.

Work based programs that are not comprehensive enough, run the risk of initiating treatment too late. Thus, they carry the cost of illness, as well as the cost of treatment. They may then carry the cost of disability or death pay outs as well.

A report commissioned by the Health Economics and HIV/AIDS Research Division of the University of Natal shows that there are obvious costs of HIV to employers and companies. These include work absenteeism, high employee benefits payouts, high employee turnover, increased medical costs, a decrease in company profits, and disruption of production (6). Staff morale and productivity are lower, even amongst staff members who are not HIV positive.

A study done by Connelly and Rosen, in 2004 (7) revealed that owners and managers of small to medium enterprises (SMEs) are aware of the effects of HIV/AIDS on their workforce but very few of them were developing strategies to mitigate this impact. SMEs could be a promising avenue of reaching millions of workers and their families to expand the delivery of HIV/AIDS services.

Small businesses need to develop programs that are both affordable and appropriate for the size of their company. Large, very comprehensive programs are not feasible or affordable.

Major barriers to the development of smaller programs include a lack of information about available HIV/AIDS services and a lack of access to these services.

Connelly and Rosen also found that the vast majority of AIDS-related attrition occurs among easily replaceable, non-critical, and/or unskilled employees. Because SMEs offer fewer benefits, have higher employee turnover, and employ fewer skilled workers than do large companies, they are less likely to capture the uncertain benefits of investments in HIV/AIDS programs than are large companies.(7)

There appear to be few tools for SMEs to develop comprehensive, affordable and effective HIV/AIDS programs, and no options developed by the South African Department of Labour to offer in-house treatment and care.

Study Aim

The aim of this study is to determine whether the services provided by the State for HIV positive patients, including the provision of antiretroviral therapy, meets the identified needs and expectations of employers in Knysna.

This information may be used to make recommendations to the Department of Health for the development and extension of ARV services.

This information will allow our clinic to improve the delivery of care to this group of patients.

Study Objectives

1. To determine the perceived effect of HIV and AIDS on local businesses.
2. To explore needs and expectations of employers in the area, with regard to HIV/AIDS care.
3. To assess the effectiveness of the ARV clinic in meeting the needs and expectations of employers.
4. To make recommendations to the Department of Health on how the ARV services could be adapted to improve access to care.

Study design

This study is a qualitative study. Employees were recruited to a focus group, and asked to explore workplace difficulties in accessing the ARV program. The information gained from the focus group was used to design a semi structured questionnaire. The questionnaire was used during interviews with local employers to explore the needs and expectations of employers in the area for the provision of health care services to HIV positive people in Knysna.

Study Population

Knysna is a small coastal town situated on the Garden Route in the Southern Cape, with a population of around 79 000 people. The study was conducted on a focus group of patients attending the Knysna ARV clinic. The study was then extended to interviews with the owners of small to medium businesses in the town.

Inclusion criteria

The inclusion criteria for employees into the focus group were:

- Patients attending the ARV clinic who were currently employed or who had been employed in the previous six months.

The inclusion criteria for businesses into the main study were:

- Businesses currently trading within the municipal boundaries of the Knysna area employ between five and 100 employees

Exclusion criteria

The exclusion criteria for employees into the focus group were:

- Patients who had never been employed, or who had previously been employed but not in the preceding six months.

The exclusion criteria for businesses into the main study were:

- businesses that employ more than 100 employees

Reliability

This was a small study. A total of eleven employers were interviewed. Although it is not representative of all the sectors operating in this town, it does give an idea of the views of the employers interviewed.

Methodology

A focus group was run with patients who attend the clinic. A semi structured questionnaire was developed and piloted and then the main study was conducted with local employers.

Focus group

A focus group was run with patients who are currently employed, or have been employed in the last six months. This allowed access to patients who may recently have lost their jobs. Eight participants were randomly selected from patients fulfilling the above criteria, and invited to participate in the focus group. All the participants who agreed to be interviewed were men. The focus group had four participants. Unfortunately, the patients who have the most difficulty in accessing the clinic, i.e. who are at work and not able to access treatment, were unlikely to be present in the focus group, and their input was not captured. Similarly, patients who have already lost their jobs, may have been over represented, as they would not be currently employed and thus have no job related time constraints and less difficulty in accessing the clinic. Women were not represented.

The focus group was asked to discuss any problems in accessing care at the clinic, with reference to their employer and employment. The themes arising from the focus group were incorporated into a semi structured interview questionnaire. This questionnaire was used to elicit data from employers, to answer the study question.

The themes were as follows:

- ❑ Confidentiality and disclosure to others (stigma)
- ❑ Trust
- ❑ Financial issues
- ❑ The right of employees to take sick leave

Main study

A pilot interview was conducted with a local employer. This was a convenience sample.

The recruitment of the main study participants

“Find it SA” who produce an online, as well as published, list of businesses and service providers in South Africa. They have a specific section in their directory for the Garden Route area. I used this resource to gain an overview of what businesses and sectors were operating in the town.

The Find it SA business directory stratifies all businesses listed into subcategories. These include accommodation, eating/drinking/going out, retail and wholesale, animal care, community info, health and beauty, homes/property/building, sports, medical, professional and consultants, vehicles and boats, service providers and travel/leisure and adventure. A random number generator was used to select businesses to participate in the study. Each business was personally contacted by the researcher, and recruited for the study.

Although the researcher attempted to obtain a random sample of businesses in Knysna, a number of businesses declined to join the study on hearing the subject matter. In a number of the sectors, there were no businesses at all that met the inclusion criteria and were willing to participate.

Because of the small number of eligible number of businesses who agreed to participate, not all the respondents were chosen from the business directory. Instead, a purposive convenience sample was used. One of the participants was recommended by another participant.

Most of the interviews took place at the interviewee’s place of business and most were done during office hours. All respondents signed consent forms and all agreed to be recorded. Before the interviews began, it was stressed that the businesses had not been chosen because

their employees were known to be HIV positive. The interviews took varying lengths of time, but all were concluded in less than eighty minutes.

Once the interviews were completed, the results were collated and analysed.

Bias

Not all eligible businesses are registered with the business directory. It is likely that eligible, but smaller, or emerging businesses may not be registered with the directory. These small businesses may have the least capacity to deal with HIV/AIDS in the work place. Employers who are concerned about HIV, and whose businesses have been affected by HIV, are more likely to agree to participate in the study and their views may be over represented.

Methods of analysis

The semi structured interview explored five main areas:

1. What is the impact of HIV on the business?
2. Who has the responsibility for HIV testing and care?
3. What are the rights of the employer versus the employee in the workplace with regard to sick leave and HIV?
4. What knowledge does the employer have regarding HIV and its mechanisms? What knowledge does the employer have regarding the services that are currently available?
5. How can the ARV clinic meet the needs of the employer? Employers were asked to rate some suggested interventions.

Once the interviews with the employers were complete, the responses were collated and analysed according to the areas above.

Ethical aspects

Knysna is a very small town. HIV/AIDS and business practice are both extremely sensitive and emotive areas in which to conduct research. The focus group participants were reassured that no individual patients would be identified to their employers, and that their treatment and care would be unaffected by their participation and responses to the focus group discussions.

During the interviews, the researcher was careful not to identify themselves as the “ARV clinic (AIDS) doctor” to the employers. However, some of the employers were aware of the nature of the researcher’s work.

Informed consent was obtained in all cases and no funding was received from any donor during the study.

Resources

This was a small study, with limited numbers of participants. No incentives for participation were offered except refreshments to the focus group participants. Any transcriptions of the data from the recordings were done by the researcher. All printing costs were borne by the researcher. A small honorarium was paid to the ARV clinic staff member who facilitated communication during the focus group interviews.

Results of the interviews with employers

All³ of the employers interviewed were aware of HIV/AIDS and were, to varying degrees, concerned about the threat that HIV posed to their effective business functioning and financial success. All the employers, without exception, wanted to help and be involved in the care of their employees.

Almost all employers struggle to absorb the costs of sick leave of their employees.

There had been eight staff deaths between the respondents. Three employers said they had definitely experienced staff deaths due to HIV/AIDS. Some of the employers who had experienced staff deaths said that although they did not know for certain, they were reasonably sure that HIV/AIDS had been the cause of death.

Almost all of the employers thought that the government was responsible for providing access to HIV testing and care. Most employers would be prepared to pay something towards annual HIV testing and care, up to about R100, although some employers would not be prepared to pay anything at all. One employer said he would be prepared to pay more for a more valuable employee, i.e. someone who is more skilled, up to R500.

Most employers know that the diagnosis of an employee is confidential, but were open about wanting to know what is wrong with an employee who is “off sick” from work. Most employers were suspicious of doctors, especially those who wrote “a lot” of sick certificates.

Employers in the manufacturing, construction/building, and hospitality sectors had health and safety concerns. Most employers were aware that many HIV positive patients are co-infected with tuberculosis.

³ Due to the small number of respondents, it seems clumsy to translate all the results into percentages. Instead ‘almost all’ means more than 75%. ‘most’ means 50 – 75%, ‘some’ means 25-50%, ‘few’ means 0-25%, ‘None’ and ‘all’ are self explanatory.

All the employers complained that employees spent long hours in the queues at the local provincial services: both at the hospital and at the Primary Health Care Clinics. There were concerns that going to hospital is “an all day affair”, even for just collecting chronic medication.

Most of the employers were aware that there were services available that are specifically aimed at HIV positive people. A few of the employers knew where the clinic is situated and the opening hours.

Almost all the employers had heard of ARVs or HAART. However, in general, knowledge about aspects of HIV care was very poor amongst employers. All the employers felt that they did not have enough information about all aspects of treatment and care.

Most of the employers agreed that a model of care which included the extension of services till 8pm during the week and Saturday mornings would improve services.

Most employees agreed strongly that the government should fund sick leave pay for HIV related illnesses.

Employers were asked to make suggestions for improving the services for patients and employers. Suggestions included:

- Running a workshop for employers about HIV
- Increasing the awareness of the HAART clinic with employers
- Making more information on the ARV clinic services available at the workplace
- Providing more “private” ARV services, e.g. with appointments
- Improving the emotional support base for patients outside the clinic
- Improving the flexibility of the ARV clinic and the Primary Health Care Clinics to deliver care
- Improving communication between the clinic staff and the employer to facilitate both the patients’ needs as well as that of the business
- Considering a change in the way medicine is dispensed

- Extending mobile services for HIV testing, treatment and care
- Splitting ARV service delivery between the private and state sectors
- Reducing the waiting times at the Primary Health Care and ARV clinic
- Extending clinic closing times to accommodate healthy patients at work

Discussion

SME employers interviewed for this study were acutely aware of the actual or potential impact of HIV on their businesses. Employers not only listed actual costs like sick leave payment or absenteeism, but also had an awareness of the indirect costs of lowered productivity and poor morale.

The economic recession and the added cost of sick leave means that paid absence from work, even to access treatment and care, is an emotive topic. In these circumstances, sick leave certificates that do not list the diagnosis are regarded with suspicion by employers, and erode trust in the services provided by the clinic.

While some employers were aware of local HIV services, accurate knowledge about the HIV virus is very poor. Almost all employers complained about long waiting times at clinics and the inability to make specific appointments. These factors hamper access to care and the findings echo those of other local studies done.

Although free and effective local services exist, taking time off work is expensive for both employee and employer. The lack of trust between employees and employers makes requesting time off from work to attend the clinic difficult for employees. Some employees do not ask for time off in advance, but present certificates for their absence on their return to work. Poor communication makes work place planning difficult for employers. This makes combining clinic attendance and work commitments an area of ongoing conflict.

Employers all felt that the government had responsibility both towards the employer and the employee, in terms of HIV care. Employers want employees to know their status and motivated strongly for expanded testing opportunities, especially at work. Even though employers did not necessarily want to know the results of these tests, they wanted regular counselling and testing to be available for workers. Employers felt strongly that the extra costs of HIV care (both for the employer and employee) should be borne by the government in increased sick leave benefits.

None of the models of HIV care that are suitable for larger businesses are appropriate for these employers. However, suggestions from local employers to improve services were very useful.

Providing HIV information to the workplace, that lists available local resources, may increase uptake of services. Multidisciplinary HIV education workshops for employers could be run through local business structures, by the Department of Health. This would also provide a platform for the Department of Labour and the Department of Social Services to advise local businesses. Improving communication between clinic staff and the employer (while maintaining confidentiality) may be crucial to decrease frustrations for all. A schedule of potential visits required to the clinic and an opportunity for the employer to input which dates suit them the best, could assist employers to effectively plan their work schedules, without compromising patient confidentiality. An efficient appointment system could be developed to decrease clinic waiting times, and the extension of opening hours to increase access to care should be considered. The extension of services outside of normal working hours may increase access to care, but would require careful planning and implementation.

In retrospect, the study results are limited by the format of the interviews. Using a semi structured questionnaire meant that the study design was not that of an in-depth qualitative study. During the interviews, the researcher attempted to gauge the response of employers to a number of proposed interventions, using a rating scale. This would have been more suited to a study in which there were larger numbers of randomly selected participants. A more open ended questionnaire may have provided more qualitative findings.

Although the study population is not representative of all the businesses operating in Knysna, it gave our clinic valuable insight into how our services are perceived by the local businesses who participated. It is not possible to generalise the recommendations to all employers, but it may provide food for thought for program developers. The strength of the study is that the results allow our clinic to respond to local identified needs.

Recommendations

1. The ARV program should look critically at the number of visits required for accessing ARV treatment and care.
2. The functioning and flow of patients through the ARV clinic in Knysna needs to improve to reduce waiting times and improve efficiency.
3. Workplace HIV/AIDS literacy materials (with local content) need to be developed. They should contain information relevant to both employers and employees. They should contain workplace health and safety information, and confidentiality and disclosure guidelines.
4. HIV/AIDS literacy workshops for employers and employees need to be developed and run in the Knysna area. Counselling and testing opportunities at work should be extended.
5. The extension of the ARV clinic opening hours to improve access for healthy, working patients should be considered.

Conclusion

What employers need is simple: to have healthy employees at work. While employers want to help their employees, none have the resources or expertise to provide or subsidise HIV treatment and care. Ignoring the needs and expectations of local businesses causes conflict between employers and employees. It is under these circumstances that employees choose between their health and their jobs. In order to increase access to care and reduce our recurrent defaulter rate, we need to look at what accommodation our clinic can make to the expressed needs of our local business community.

It is unlikely that the concerns expressed by local businesses in Knysna are confined to our small town. As the ARV program continues to expand, these issues are likely to be occurring at other roll out sites. As the number of healthy patients remaining in care continues to increase, these issues may become a priority for employees, unions and other organisations that support workers. The Department of Health, the Department of Labour and the Department Social

Services need to work together to address the needs of health care workers, employers and employees.

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