

UNDERSTANDING HIV/AIDS COMMUNITY NURSING CARE

The Royal District Nursing Service of SA Inc (RDNS) provides community nursing services to People Living With HIV/AIDS (PLWHA) and has done so since the late 1980's. Two specialist community nurses provide this care, underpinned by the broader nursing service. The support and home-based care provided to clients by the HIV portfolio is based on a foundation of district nursing principles and standards of care, together with expertise gathered over time. However, a specific model of care articulating the detail, philosophy and core principles of the care had not been developed. In this newsletter we report on a project that developed a person-centred model of care and philosophy to guide RDNS HIV/AIDS community nursing care.

WHAT WAS THE ISSUE?

Over the past decade in the developed world, HIV disease has been reconceptualised from an acute epidemic to a chronic disease (Berridge 1996). During this time, the needs of PLWHA has shifted, with people requiring long term management and support in the community. HIV, however, has continued to attract stigma, with people learning to live with HIV/AIDS bearing the brunt of the stigma and discrimination, thus impacting on their quality of life.

Living longer with HIV/AIDS is associated with long-term complications and more complex care needs, particularly in relation to medication therapy. The development of Highly Active Anti-retroviral Therapy (HAART) has resulted in PLWHA being able to live independently and needing to access intermittent care from primary physicians, community nurses and other health workers. Many PLWHA are referred to health care organisations because of the complex nature of their situation and, as such, these organisations are faced with challenges in improving client outcomes. PLWHA have complex medication and treatment regimes; they may have complex co-morbid diagnoses that require ongoing intervention, liaison and support. For these reasons we considered it important to have a model of care and philosophy to guide community nursing practice when working with people with HIV/AIDS.

WHAT DID WE DO?

The aim was to gain a better understanding of our practice by exploring the literature, interviewing and conducting workshops with the CNCs to explore practice, and interviewing clients to gain their perspective of our practice.

Following analysis of each of these data sets it became possible to:

- develop the core principles of practice,
- develop a philosophy to guide practice, and
- develop a model of HIV community nursing practice.

LITERATURE REVIEW

Providing care to PLWHA can be complex, involving varying states of disease progression, an unpredictable disease trajectory, diverse client characteristics and needs, and barriers to accessing health care, such as discrimination. Often, multiple service providers are involved in care which makes the standardisation of care difficult (Van Manen et al., 2005). The question of what constitutes an optimal care model had not been answered previously because the focus had been mostly upon biomedical perspectives and drug therapies. There was a need to articulate models of HIV/AIDS care, particularly in a community setting and especially in a nursing context. Some common themes were evident that informed model development. These were:

- A care approach based on the principles of primary health care is associated with better outcomes for PLWHA (Hecht et al., 1999; WHO, 2002; 2005; Cooney, 1994; McDonald & Hare, 2004; Centre for Health, Equity, Training, Research and Evaluation CHETRE, 2004)
- Case management had been associated with improved client outcomes (Katz et al., 2001; Shelton et al., 2006; Gardner et al., 2005; London et al., 1998; Hesselgrave & Richardson, 2006)
- Multidisciplinary care and support services significantly increased access to, and retention in, primary care and resulted in better care and improved outcomes (Sherer 2006)
- The relationship between the healthcare worker and the client is seen as an essential foundation for tackling difficult and sensitive issues associated with the experience of stigma and discrimination. The relationship involves a partnership which centres on trust, acceptance and a non-judgemental attitude (Jonsdittor et al 2004).

THE CLIENT PERSPECTIVE

Three long-term RDNS clients with HIV consented to be interviewed about their experiences of being the recipient of specialist nursing care. The interviews lasted between 1.5 - 3 hours. Ethics approval was obtained and pseudonym names were used to protect the identity of clients. The real names of nurses have been used because

they are well recognised in their field.

The interview data was analysed simultaneously with the literature. Analysis utilised a constant comparative method with the aim of eliciting meaningful units and themes. Client perspectives were central to informing the RDNS model of HIV/AIDS care. The main themes were:

'Back on Track'

Participants revealed a contrast between their life prior to being connected with RDNS and afterwards. They regained order and control in their lives. Craig and Neville talked about the changes in their lives since accessing RDNS:

"...it was also my fault too because having the disease and sort of a defeatist attitude and I was drinking a lot... and so I just went downhill when I first came to Adelaide. And then I met up with Ann and then all of a sudden I got back on track again." (Craig)

"I can honestly say that getting involved with Dean and the RDNS saved my life, because at the point that I met Dean, I was at a really low point in my life... and I've always suffered from depression, and I feel that if I hadn't have met Dean, I wouldn't be here. I would have killed myself." (Neville)

'Now I'm pretty good with taking my tablets'

Medication is often a reason for receiving RDNS care. Participants had complex medication regimes that they had not managed well prior to the involvement of RDNS. *"...and that's how I met up with Ann and then started on the prescription... or the anti-virals... and touch wood it worked, so it was good"*. (Craig)

Monitoring – 'the first line of defence'

While regular contact to organise medications was often the primary reason for RDNS visiting, it was also an opportunity for monitoring clients' broader health and social situations. Neville found this reassuring:

"... with Dean coming around... okay, he comes here to fill the dossette box, but he's sort of like my primary intervention. If something's going wrong, then he will encourage me to go and see a doctor, or sort something out. ...he's like my first line of defence."

A focus on rights

Care provision was an opportunity to remind people of their rights in the face of discrimination and stigma. People felt supported. Craig describes Ann's response to a doctor's negative reaction:

"And I had all the support in the world, so... Ann, of course... RDNS nurse... she was 110% behind me, you know, so... and she said [of the doctor], "You just can't say those things... you can't do that," you know... as far as discrimination."

Valuing of the person - acceptance, understanding and non-judgemental approach

A non-judgemental nurse was critical for these clients. Nurses demonstrating acceptance enabled people to feel safe. Neville said:

"You know, it's just knowing that I've got a group of people there that understand me, and understand my disease and why I'm feeling the way I feel, and... why I act the way I do when I'm feeling depressed...whereas

other people would just say "stop whinging" whereas they're prepared to sit and listen and help you work out, you know... work through your problem."

Relationship – 'A different connection'

A long term client/nurse relationship is important. The professional relationship crossed into the personal realm in order to provide a basis for ongoing monitoring and the tackling of difficult issues. Craig said:

"Friendship is one of the main things I think... with Ann ... I've bonded with Ann for 10 years and we've just got the greatest friendship, you know, and that's just ongoing. So it's not only on the professional side, it's also on the personal side. She's a good friend and a good mate, and she always has been. And I'd say I can ring her up any time and ask her questions, or if she'd be able to do something for us, or vice versa, and there's no problem."

Simon described his relationship with Dean as, *"a friend, someone that I can confide in about anything. I trust him. I can ask medical questions... you know anything I'm concerned about. I'm not frightened to ask him now"*. The close connection enabled honesty and 'straight talking' between nurse and client, even on sensitive issues. Neville said, *"and you know, I've discussed it, and I'm happy to be frank with [Dean], and he's happy to be quite frank back!"*

Being linked with 'other people and places'

Clients valued the role of the specialist nurses in linking clients with useful people, services and groups that assisted them to deal with HIV/AIDS and relieved some of the burden of life with HIV:

"... from her I got to know other people and places and everything, and so... so my problems – I could talk to other people about them through Ann and the places that she told me to go to, you know... for links." (Neville)

Neville became involved in the HIV/AIDS service community following some resistance:

"... he is willing to persist with me because he knows that ... I'm stubborn when it comes to being involved with things. Dean's helped me to get involved with the Positive Living Centre (PLC) and Adelaide Diocesan AIDS Centre (ADAC)... the AIDS Council...because prior to meeting Dean, I never knew anybody else that was HIV/AIDS positive. It was too scary."

Information and education

Specialist nurses provided information and education enabling clients to understand more about HIV and identify their needs. Craig explains how it has helped him to access assistance, *"[Ann] has given me the information so that I can actually go out and get the help if I need it... for most things..."*

The specialist nurses found specific information for the client as Simon explained:

"It's information and education, and he... is really good. A number of occasions that I'm interested in such and such, and he'll get on the net and get a whole lot of articles and then drop them off."

Feeling connected to a network

People were linked to a network of people and services

that could assist them with different aspects of care. The network made a difference to Neville:

"I have a very good relationship with my doctor and with Dean and with my counsellor. You know it was a really scary thing because you didn't know who to talk to about this sort of stuff."

Insight – 'out of a bad thing has come a good thing'

Learning to manage HIV/AIDS enabled clients to gain insight into their experiences. Adversity bought with it some benefits for Neville.

"I don't feel sorry for myself in regards to what's happened to me; I actually feel that I've benefited from my illnesses...By having to go through a lot of struggle is... I feel has actually made me a better person and I've had to seek out and learn to get help from other areas".

Craig considered there to be a positive side to the experience of HIV/AIDS, *"...out of a bad thing, has come a good thing in one respect because people can converse and mix together and discuss things, which is a big help".*

'They do a wonderful job'

The satisfaction expressed by participants about the care provided by the CNCs: HIV/AIDS revealed that the service made a difference in their lives. Craig said, *"...if they only knew that people like Ann are out there, and to help... and they do a wonderful job with it. I couldn't be more pleased."*

Neville said, *"...for years I fought to not be involved with all of this sort of thing, and then once I actually found out about it, it opened up a whole new world to me, so I, myself, am very happy with the service I get from the district nursing"*

Clients' identified a process of adaptation to the illness that occurred as a result of the support provided by RDNS. Adaptation was evident by the personal growth experienced and identification of some benefits of living with HIV/AIDS.

NURSES' PERSPECTIVES

The two CNCs were interviewed by the research team, the detail of which is in the full report available on the RDNS Intranet. Responses of the nurses were grouped into themes, which were analysed with the other data sets to shape the model of care. Themes were: Continuity, More than Medication, Person-centred practice, The Relationship, Linking people with community resources, Ongoing monitoring, Providing Practical Support, Counteracting stigma and discrimination, Empowerment, Working at the community level, Providing care across the continuum, Confidentiality, Advocacy and The place of care.

Due to the complex nature of HIV care, each of the themes could be present in any one client interaction. The responses from the nurse interviews paint a picture of a model of care that is embedded in primary health care principles such as accessibility, continuity, care across the continuum, education, empowerment, social justice and collaboration with other organisations in the community.

What stands out from the specialist nurses responses is that the person is prioritised in decisions about their

care. A humanistic approach ensures that people are consulted and information about options are given, along with time to consider and discuss their implications. Ultimately, the decision lies with the person. While the CNCs: HIV/AIDS admit they have an agenda about what needs to happen, they work with the person to enable the person to gain insight about what needs to happen, rather than impose it.

PULLING IT ALL TOGETHER INTO A MODEL AND PHILOSOPHY OF CARE

The model of care seeks to resource the person in a way which develops their skills and abilities to take responsibility for their health and lifestyle decisions. It seeks to rebuild the autonomy and independence of the person so that they regain a sense of personal power and confidence in themselves. By providing people with information that enables them to understand HIV/AIDS and by connecting people with the resources and services that will improve their overall wellbeing, some are able to adapt and move forward with some hope. The combination of interventions carried out in order to care for the person and create a supportive environment, work against the powerful negative forces in the social environment. Collaborative work with other organisations in the community strengthens efforts to raise awareness about HIV/AIDS, counteracts discrimination and provides support to PLWHA.

The relationship was at the core of this way of working. People were treated respectfully, without judgement, and valued as individuals. The CNCs: HIV/AIDS work to develop a trust, confidentiality and honesty that create a platform for working together on sensitive issues. Importantly, people felt safe to confide aspects of their lives they may not have shared with others.

Ultimately, the RDNS CNCs: HIV/AIDS approach to care shifts the burden of HIV/AIDS away from the person by:

- Counteracting the effects of negative attitudes and a hostile environment; providing them with a positive relationship in which they are valued and respected without judgement. This fosters self-esteem and confidence and is an aspect of care which is highly valued by participants
- Creating an environment which is responsive and supportive by connecting them with a network of community resources and services and by providing ongoing monitoring and support
- Assisting people to understand and learn to live with HIV/AIDS through information and education
- Alleviating the stress of complex medication therapy
- Assisting participants to reclaim a sense of control and power in their lives
- Providing intensive and comprehensive support.

The research team facilitated a number of workshops for the project management team in which nursing practices were explored and core principles identified. These are described in detail in the complete report and are central to the development of the model and philosophy statements. The model and philosophy are a synthesis of all the data from the literature, the interviews with clients and staff and the workshops with the project team.

The Philosophy of RDNS CNCs: HIV/AIDS

"We work towards an increased quality of life for those

infected with or affected by HIV/AIDS. The dignity of people infected with or affected by HIV/AIDS is affirmed by our practice approach of building innovative partnerships that meet the short-term and long-term challenges raised by HIV/AIDS. We believe that people living with and affected by HIV/AIDS have a right to accurate information and empathic support that will enhance their capacity to manage their own health care through informed choice. We provide information and nursing care in a way that is non-judgmental and respectful of an individual's right to self-determination."

Model of RDNS HIV/AIDS community nursing care

The elements of the model (refer to diagram) are:

The person as central - the innermost centre of the model represents the person living with HIV/AIDS. The person is at the centre of decision-making and activity.

The relationship between the person and HIV/AIDS specialists offers resistance to negative social forces - most importantly it is the relationship through which care happens. There exists a dynamic interplay of positive and opposing forces.

The opposing forces are represented by the grey wedges. The social forces shape the experience of learning to live with HIV/AIDS. The relationship, care and interventions are viewed as positive forces that serve to resist the negative impact of the social and environmental forces such as stigma and discrimination. Activities and actions that occur in the model of HIV care seek to reduce and minimise the impact of negative environmental pressures and to boost the person's personal and social resources to cope with living in an unsupportive environment.

The core practice principles and goals are in direct response to the impact of the disease and the social forces—intervention at the individual and community level is in response to the social and health consequences of the experience of HIV. The model focuses on the individual in their community. Individual support is reinforced by connections, nursing actions and interventions at the community level. Comprehensive and responsive care is shaped by individual needs.

CONCLUSION

Involvement in this research has been inspirational for our practice. Prioritised in these findings are the voices of PLWHA who revealed that the model of care makes a difference in how they feel about themselves and their life. For some clients, it has made the difference between life and death.

The high value placed on the relationship with the RDNS CNCs: HIV/AIDS is at the core of the model. A non-judgmental, empathic relationship is important. While PLWHA experience this as friendship, they recognise that it is an extension of a professional

relationship. The specialist nurses cross into the personal realm in order to establish a depth of familiarity and closeness important to equal power relations and ongoing work together.

The focus on partnership and the way HIV/AIDS care seeks to counteract negative forces in the environment is evidence that the model is informed by a comprehensive primary health care framework.

A separate project within RDNS, developing core competencies for nurses at all levels, is utilising the outcomes of this research as a basis for some of the more generic skills or qualities sought after in nurses working with clients in the community, particularly where those clients may belong to one or another stigmatised or marginalised group.

The full report for this HIV/AIDS research project can be found on the RDNS Intranet under Research Publications.

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