A Phenomenographic Approach To Examine The Different Ways HIV Patients Understand The Experience Of Counselling

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Abstract

This paper describes the outcomes of research examining the different ways a group of HIV patients understood their experience of counselling. Many studies have been done in relation to types of counselling and evaluation of the effectiveness of counselling for HIV infected persons. However, no research has specifically analysed patient understanding of the experience of counselling. Having an insight of the counselling experience in HIV sufferers and understanding of what they have achieved from their experience is important and relevant to counsellors and other health care professionals as it can assist them to better respond to the needs of people with HIV and meet their expectations of health care workers. A phenomenographic approach was chosen to inquire into the qualitatively different ways of understanding the experience of counselling. The research results are presented in the form of four ways of understanding and an outcome space representing the logical relations between the counselling experience. The research confirmed that the counselling experience is understood and experienced as a way of assisting individuals who are seeking to accept the need to live with the presence of an infectious disease. Counselling assisted the HIV patients involved in the research by providing reassurance and comfort, because the news of the disease emotionally affected their lives. Counselling provided necessary information about the disease process, educated them about cultivating an appropriate lifestyle, and was a mechanism for mediation with family and friends. Unlike other diseases, findings reveal that individuals with HIV experience immense limitations to their lives due mainly to issues related to social stigmatisation. The research results inform health care professionals of patient experience and assists to further our understanding of both people with HIV and their expectations of health care workers.

INTRODUCTION

This paper presents finding of a study that examined the qualitatively different ways two people diagnosed with HIV understood their counselling experience. There is limited research examining the way counselling is understood by people with HIV. Carballo and Miller (1989:121) note that the WHO/GPA define counselling for HIV as 'an ongoing dialogue and relationship between client or patient and counsellor with the aims of preventing HIV transmission and providing psychosocial support for those affected, directly then indirectly, by HIV'. Counselling can include health education, primary prevention of HIV infection, strategies to effect behaviour change, support to both partners and families, bereavement counselling, staff support, liaison and consultation with colleagues, psychological interventions, and counselling for therapeutic drug trials (Bor et al., 1991).

There have been many studies which confirm that counselling therapies reduce stress, anxiety and depression for HIV positive people (Begley et al., 1994; Catalan, 1995). However, limited research has examined HIV patients' experiences of counselling therapy. The complexity of challenges confronting people with HIVIAIDS and the psychological terror it creates can often affect every aspect of a person's life. People with HIV can experience anxiety, fear and depression. In such cases Begley, Ross, Austin, Casey, Collins, Hennings, Agriesti and Marshall (1994) recommend that counselling therapy can decrease psychological symptoms such as depression and anxiety. Their study reported that the effectiveness of counselling is revealed as changes to mood states (Begley et al., 1994). Visser and Antoni (1994) add that psychosocial interventions can also strengthen social support for HIV sufferers and assist to change behaviour by educating people

in matters such as the danger of drug users sharing needles. Due to the life-threatening nature of the disease, its psychological and social impact, and the legal issues involved, it is assumed that HIV counselling plays an extremely vital role in each person's personal growth (Hicks & Rundell, 1996). For example, there are likely to be mental health risks for people who have contracted HIV. For example, Marzuk et al. (1988) noted that there is a significant increase in suicidal risk for people who have contracted HIV. It was noted that people with HIV infection have a 66 times higher suicide risk than that of the general public. Results of research undertaken ten years later (Markowitz et al., 1998) found also that depression is a major mental health problem for people who have contracted HIV. Importantly, it must be noted that Kelly and Murphy (1992) and Markowitz et al. (1998) found that psychological levels of distress for people had generally improved in recent years due to the effectiveness of medical treatment regimens and the adequacy of counselling and psychotherapy.

The purpose of this research was to explore the different ways a small group of HIV patients understood their counselling experiences. HIV is known to create stresses that are associated with social stigma and feelings of loneliness, and diagnosis of HIV can lead to suicide attempts (Miller, 1995). Given that counselling is an avenue to assist people, it is worthwhile examining the qualitatively different ways people understand their experience.

RESEARCH PURPOSE

The complexity of problems confronting people with HIV and the psychological terror it creates can affect every aspect of a person's life. The aim of the research described in this paper was to identify ways of understanding the experience of counselling and was directed by the research question:

What are the qualitatively different ways that HIV patients understand the experience of counselling?

THE PHENOMENOGRAPHIC APPROACH

Phenomenography is a research approach that aims at the mapping of the qualitatively different ways that people experience, conceptualise, perceive, and understand various aspects of, and various phenomena in, the world around them' (Marton, 1988:178). The major characteristics of phenomenography are concerned with its attempt to capture conceptualisations that are profound to the experience of a selected phenomena, the categorisation of different ways of understanding, and presentation of the logical relations between understandings.

Phenomenography is a second order perspective that describes the different experiences of phenomena that occur to people in particular contexts. The ways of understanding experiences are the principal theme of interest (Bruce, 1997). Qualitatively different ways of understanding experience are divided into different categories of description that capture the meanings or conceptions of their experience (Marton & Booth, 1997). The logical relations between categories of description are identified and described further in the form of an outcome space. Marton and Booth (1997:125) explain that the outcome space is the formation of 'complex categories of description [conceptions] comprising distinct groupings of aspects of the phenomenon and the relationships between them'.

Categories of description and outcome-space are the results of a phenomenographic research and serve as tools to capture and communicate the ways of understanding the phenomena under investigation (Barnard, McCosker & Gerber, 1999; Bruce, 1997 ; Svensson, 1997). The inter-relations between categories of description thus created are often portrayed diagrammatically and are an empirical map (outcome space) of the qualitatively different ways of understanding phenomena. Marton (1988:181) states that the final outcomes of phenomenographic research are descriptions that are relational, experiential, content-oriented and qualitative.

1. Relational, as they relate to patients with HIV and their relationship with counselling;
2. Experiential, as their experience of counselling dominates their thoughts and knowledge related to HIV;
3. Content-oriented, as the descriptions of their perceptions and experience are based on the their counselling experience; and
4. Qualitative, as four different ways of understanding counselling emerged from analysis of data.

Although there are similarities between phenomenography and phenomenology, particularly in relation to the rules of interviewing and the overall object of research, the two approaches should not be confused. Phenomenographic results focus on the descriptive level of participants

understanding and research is presented in a unique empirical manner as categories of description and an outcome space. Phenomenography does not engage in the psychological reduction of data. The approach is interested in emphasising collective meaning rather than individual experience, and emphasises reflective rather than pre-reflective experience. Phenomenography is phenomenal rather than noumenal and aims at describing the world as it is understood rather than the world as it is. As in phenomenology, the intention is to describe the world as people experience and explain it; however, phenomenography arrives at a different level of description.

RESEARCH METHOD

SELECTION CRITERIA

After ethical approval to conduct the research two people admitted to an infectious disease unit in a large Australian metropolitan hospital were invited to participate in the research. Participants were selected on the basis of convenience and were both involved in ongoing counselling. Their participation was voluntary, and that they had the right to discontinue their participation at any stage of the research.

DATA COLLECTION

Data collection consisted of a tape-recorded semi-structured interview. The aim was to bring forth the interviewee's awareness of his or her own insights into the experience of HIV counselling. Interview questions were oriented towards the experience under investigation. Discourse directed each participant to describe counselling and consider their experience based on questions such as 'What is your personal experience of counselling?', 'What have you benefited from the course of counselling?', and 'in what way do you think it has/has not helped you?'. All the elements of the study, including the data gathering and analysis, were guided by the research purpose and the need to achieve the outcomes of the research (Bowden, 1995). During the data collection phase, participants were prompted to reflect on their understanding of their counselling experience.

DATA ANALYSIS

Data analysis consisted of four phases. Phase one included reading through transcripts to confirm their accuracy and listening to audio-taped interviews in order to (re)familiarise the researcher with discussion. Phase two involved a process of identifying the meanings hidden within the discourse. Marton (1988) states that there are two contexts to quotations: the interview from which it is taken and the "pool of meanings" that arise from the discourse. Svensson (1985) explains that the analysis phase of a phenomenographic research involves a process of comparison of data and the identification of patterns between instances and individuals that describe meaningful categorise. In addition, interpretation of quotations throughout the analysis phase was based on the context of experience. Thus, quotations were highlighted from interview transcripts and discourse was interpreted within the scope of the meanings expressed by each participant across an entire interview.

Phase three involved the organisation of the results of analysis into categories (groups) based on similarity and difference in meaning. Quotations were sorted into groups and then organised on the basis of standard characteristics that defined each group. Phase four completed the analysis and involved a process of reduction in which groups of quotations were refilled into discrete categories of description on the basis of similarity and difference. The researcher's interpretation of logical relations between the various categories were compared and contrasted in order to confirm and outcome space.

WAYS OF UNDERSTANDING THE COUNSELING EXPERIENCE

As a result of the analysis four qualitatively different ways of understanding were identified as a result of counselling experience. The four qualitatively different ways of understanding the counselling experience of patient's with HIV are:

Table one: Ways of understanding the experience of HIV counseling

The four categories of description are described according to the data obtained from participants, and are labelled to describe experience based on linguistic expression and the researchers interpretation of the understanding of participants. Each category of description (conception) reflects the relation between the participants and the phenomenon of counselling. The results of the research are in accordance with the recommendations of Marton and Booth (1997:125) who explain that in phenomenographic research, the criterion for the validity and truthfulness of each category of description is that they' stand in clear relationship with the phenomenon of investigation' and have also 'a logical relationship with one another'. This study has been undertaken in accordance with the tenets of

phenomenographic research and there are clear and logical relations between each of the four identified conceptions.

Conception One: Counselling provides reassurance and comfort.

Counselling provided participants with increased reassurance and comfort. Counselling was described as their most important experience since learning they were HIV positive. The experience is described by the following person who stated that:

It certainly helps me, knowing they are there. For absolutely anything I want to speak to them about you get so close to them (Soon, 1999:68).

Being reassured and comforted were viewed as being included in a caring and committed environment. One of the participants realised for the first time that counsellors could be kind and accommodating. The experience made him less fearful of unknown aspects of the disease, symptoms of illness, rejection from people, and fear of being stigmatised.

Participants described counsellors as a friend and the next best person to family. That is: someone with whom they could share their most personal problems and intimate thoughts. Consequently, they built a good rapport with their counsellors and were able to share their most personal challenges. The experience is explained by the following participant who highlighted that:

Everyone has got to have someone. They're not only counsellors, they're friends, they do far more than their job expects. Just so you're content in your life. The counsellor is prepared to listen and help you along (Soon, 1999:70).

Conception Two: Counselling is an avenue to obtain information and education.

The experience of participants highlighted the need for people to obtain updated educational materials about HIV. For example, the participants expressed the need for more information about modifying their lifestyles and ensuring they did not pass on HIV to others. Their experience confirmed the desire of participants to be educated about their disease and lifestyle. Participants attended counselling to obtain information and the importance of the experience is emphasised by the following person who explained that:

If I had a partner...I would take him to the counsellor... if they 're negative or they're positive, either way, that they're informed so that they knew what was going on if they know nothing about it (Soon, 1999:72).

Information and education related to sexual intercourse and drug use, as well as observing for signs and symptoms of infection were described as important outcomes of the counselling experience. Counselling provided information that was relevant to participants and assisted them to maintain their health. They felt better able to be responsible for their actions and future behaviour. Information and education allowed them to plan a modified lifestyle and to learn to live with their disease.

Conception Three: Counselling mediates between patients, families and friends.

Participants expressed the need to meet others with similar problems in order to share their emotions, to form a circle of friends, and to assist family to come to terms with HIV in a positive and supportive manner. Participants experienced a need for increased support especially when first diagnosed as HIV positive. Participants explained that their families and friends did not have appropriate knowledge of HIV and some relatives choose to ostracise themselves due to lack of understanding of the disease. Because family and friends lacked knowledge there was increased need for counselling and for information that explained important aspects of HIV. As a result of counselling, participants understood that their family and friends had began to understand HIV better, and they hoped for better acceptance of each other. One of the participants emphasised that:

Because you don't want to worry your family. You've got to have a mediator there.

We've found that as well. Just in case they need assistance as well. Because what you can tell them, they might not understand, but a counsellor can re-inform them and reinforce it (Soon, 1999:75).

Conception Four: Counselling as learning to live with restrictions

Even though counselling provided support, education, and assistance to people, the assistance was limited. Participants had expected initially that with the help of counsellors they would be able to overcome difficulties such as, applying for a loan from a financial institution or obtaining prescriptions when physically unwell. However their experience demonstrated that HIV meant the need for revised life

expectations as they lived with the potential restriction and rejection that can be associated with being diagnosed HIV positive. Their experience and understanding was described by participants who noted that:

...you're sort of coping with the reality of life as it is and the frustration of the government, as in courses, if you like doing uni courses or things like that, off the record, they usually get [employment centres] and all these sort of places. It's dead money, they don't give it to you (Soon, 1999:80).

...the counsellors are knocking their heads against a wall too because they're fighting against the government (Soon, 1999:80).

The fourth conception describes the distress experienced by participants as they faced constraints whilst attempting to re-live their lives. Even though emotional, educational, and psychological support is available, the counsellors were limited in their influence over many life matters and this led to less than positive experiences for each person.

THE OUTCOME SPACE

The outcome space portrays the logical relations between categories of description based on structural and referential aspects. The outcome space depicts the how and what of experience and understanding. The structural (how) aspect of the outcome space in this research describes stages participants experienced as they proceeded with their lives after being diagnosed with HIV. The four categories of descriptions were found to relate hierarchically since they describe acceptance of diagnosis and the ability to proceed on with life. An hierarchical structure is explained by Marton and Booth (1997:125) as representing increasing complexity, 'in which the different ways of experiencing the phenomenon in question can be defined as subsets of the component parts and relationships within more inclusive or complex ways of seeing the phenomenon'. The diagrammatic representation of the outcome space (Figure 1) is a large triangle. The triangle portrays a hierarchical structure with each of the four categories of description placed within the triangle highlighting three stages associated with the experience of counselling. The referential (what) aspect of the outcome space refers to what the participants' understood about their counselling experience. As HIV disease affects every aspect of an individual's life, the relationship between the categories of description includes emotional, social and physical meanings. These meanings are inter-related and result from the participants' need to proceed on with their lives and is reflected in the following three stages.

STAGE ONE

The first stage of the outcome space (Figure 1) describes the need for reassurance to ease worry and apprehension. Due to fears associated with acquiring an incurable disease, the person needs to feel a sense of comfort and acceptance and this need can be met through counselling. Counselling was described as an experience that assisted them to start a new life. Counsellors provided reassurance for them each time they encountered a problem or experienced difficulty. It was comforting for participants to know that counselling was available when they need it. They experienced someone being there for them to share their good and bad experiences without fear of being criticised or stigmatised.

STAGE TWO

The second stage includes both the second and third categories of description. Participants entered the second stage when they began to accept their diagnosis of HIV and felt able to disclose the diagnosis to their families and friends. Participants encouraged counsellors to mediate for them, to accept them, and to educate them about the disease. During this stage of living with the illness, the participants described a need for knowledge about the disease and the ways they could relate to having HIV. Counsellors were able to intervene to answer questions and to provide relevant explanations when there was doubt or anxiety. Therefore, counselling to mediate conception can be both related to the information and education conception and the reassurance and comfort conception. Thus, the outcome space at the second stage portrayed the relations between the second and third conception.

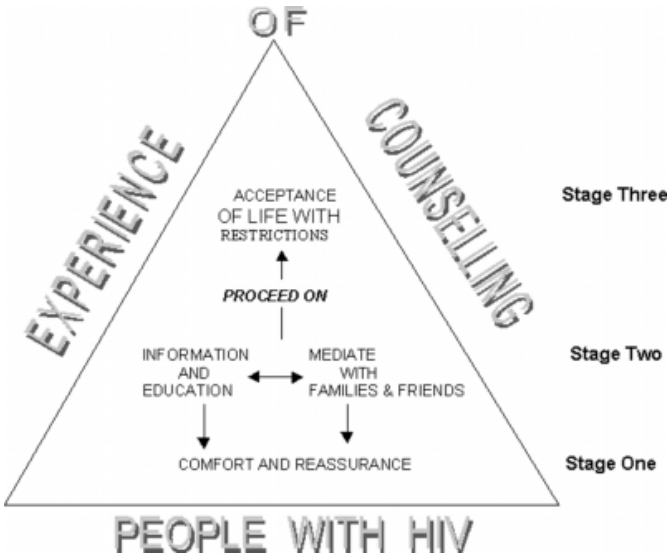
STAGE THREE

The third stage is associated with the fourth category of description. The third stage describes counselling as a source of assistance for people living with restriction. Participants believed that they had reached a stage where they could set goals and were more comfortable taking one step at a time. Participants felt less need at stage four for counselling and were able to begin to relive their life again. Participants had encountered many difficulties and felt restricted in their lives. They were judged often by others for being HIV positive and were not given financial support for example, for the things they want to do. Through counselling participants understood that life was now more challenging

for them but counsellors were seen to be people willing to extend help to them. The participants realised that they have reached a stage where they could set limited long term goals (e.g. building a house within the next five years), and they were more comfortable with "proceeding on" living one day at a time. With this level of acceptance, the participants believed that there was no further necessity to continue with ongoing counselling.

Figure 1

Figure 1: The Outcome Space: Understanding the experience of counseling



DISCUSSION

This study highlights how two people diagnosed with HIV understood their experience of counselling. Comparison between positive indications of the benefits of counselling (e.g. (Balmer, 1994; Kelly & Murphy, 1992). and the findings from this study indicates it assists emotional distress and progress towards emotional well-being for people with HIV. Participants understood their counselling experience assisted them emotionally and was gratifying. The results confirm that an emphasis on the emotional aspects of assisting people with HIV is important as counselling can help people to a reasonable quality of life (Lutgendorf et al., 1994; Morris et al., 1986). Counsellors and health professionals need to develop strategies to promote counselling as a way to provide assistance. Recently diagnosed individuals need to be encouraged to participate in HIV counselling in order to obtain additional assistance with making positive plans for the future. It has been noted by Gala et al. (1992) that many people diagnosed with HIV has refused assistance from counsellors.

Participants in this research understood their counselling experience as a process of gaining support, information and education to assist them, their families, and friends to resolve anxiety, anger and confusion. Participants experienced counselling as a way of obtaining knowledge about issues such as transmission of HIV through sharing needles, intravenous drug use, and promiscuous sex (Malow et al., 1992; Spizzichino et al., 1998). The findings highlight that health care professionals should be aware of the needs of the patients and the importance of the counselling experience for some HIV infected individuals. The research confirms the importance of health care professionals promoting counselling for people who are newly diagnosed with HIV. The outcomes of the research demonstrate that the relationship between counsellors and patients with HIV can be helpful to personal development and family relations. The four ways of understanding the counselling experience provide not only a description of experience, but a framework that enables health care workers and counsellors to gain greater insight into the progress of HIV positive people in their efforts to positively move forward with their lives.

Even though the research included only two participants, and the results may not therefore represent all the qualitatively different ways of experiencing HIV counselling, the findings confirm the research of Gala et al. (1992), who found that even though fewer than 17% of individuals (n=271) with HIV disease seek counselling assistance, it is nonetheless very beneficial for those people who do. Recommendations for further research to investigate the reason for few people with HIV seeking counselling would help in providing awareness into future care and the needs of people with HIV.

CONCLUSION

This paper reports on phenomenographic research that described the counselling experience of two people with HIV. The research identified four conceptions of counselling and an outcome space that described the logical relations between ways of understanding within three stages of experience. The conceptions revealed that counselling provides reassurance, comfort, information and knowledge, and opportunity for mediation between family and friends. Counselling assists people in order that they may learn to be confident to live again. Counsellors were found to be significant to participants. They assisted them to resolve challenges at a difficult time in their life. The research highlights the usefulness of counselling for people with HIV

and the necessity of encouraging people to take advantage of assistance when feeling apprehensive, in need of support to disclose their diagnosis to others, and when seeking to positively move forward in their lives.

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