

People Affected with HIV: Experience of Counselling Contributes to Emotional Support

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Abstract

This qualitative study aimed to investigate the impact of the experience of counselling and the emotional support that it provides of people affected with HIV in Terengganu. A total of 10 people affected with HIV participated in this study, selected by purposive sampling. Data were collected using semi-structured interviews, diary entries and non-participant observations on two occasions for every participant. The data were analysed by thematic analysis in order to identify themes related to the participants' experiences. The findings showed that the counselling sessions created opportunities for the participants to share their stories, which contributed to their feelings of being supported and understood. They also felt motivated to face their daily struggles in a more positive way. In addition, they experienced feelings of relief due to the opportunity to share their experiences with the counsellor. The feelings of being supported, understood, appreciated, motivated and relieved experienced by people affected with HIV provided them with emotional support. Implication of the findings, counselling sessions contributed to the feelings of being supported and understood, thus motivated people affected with HIV in facing their daily struggles in a more positive way.

Keywords: people affected with HIV, emotional support, counselling experiences, qualitative research

1. Introduction

People affected with HIV often experience negative feelings and behaviour. Gordillo et al. (2009) mentioned that people affected with HIV suffer from emotional disorders, such as anger and fear inherent in them. Indeed, those with HIV are more likely to experience of stigma and discrimination (Rispel, Cloete & Metcalf, 2015). It is evidenced that emotional support is strongly associated with physical and psychological adjustment in people affected with HIV (Gordillo et al., 2009). In relation to this, counselling sessions can help people affected with HIV to feel positive about themselves when facing difficulties (Soon & Barnard, 2000).

2. Literature Review

There are previous studies conducted in understanding people affected with HIV. According to Haslee Shahril (2007), people affected with HIV will experience the fear of death, a dead end in their careers, people's views and life plans and start to engage in self-denial. These negative feelings may begin at diagnosis, with affected people beginning to change their behavioural patterns immediately after testing positive, preferring to isolate themselves without doing anything. They may prefer to live alone without receiving external support (Marks, 2005) due to the stigma associated with HIV infection (Gilbert & Walker, 2009). This may cause them to experience more stress and emotional disturbances and have a tendency to commit suicide (Pursell, Fanner & Barnes, 2013).

Tudor, Keemar, Tudor, Valentine and Worall (2004) highlight Rogers's view of human development and the importance of being in a relationship. According to these authors, an individual cannot be fully human without being in a relationship. Rogers (1951) stated that relationships with others help individuals to understand themselves, contributing to positive feelings about themselves. Every individual needs positive attention and needs to be loved, liked, respected, admired and accepted by others, including family members. In real life, people do not always receive the positive attention they require; often they experience negative attention that could cause tension and stress. Furthermore, individuals often receive negative and positive attention at the same time, enabling them to manage tension and stress despite the negative attention that they receive. The human need for love and acceptance are natural, thus, relationships with others, including family members and members

of the community, are very important in developing a sense of love and affection (Rogers, 1961). In relation to the people affected with HIV who choose to live alone, do they need to experience love, being liked and accepted by others?

Emotional support has a significant role in a close relationship (Burleson, 2003). In other words, emotional support will be experienced by an individual in a close relationship with others. Emotional support helps distressed people to work through their upset by listening to, empathizing with, and actively exploring their feelings (Burleson, 1984). In addition, the support provided by close relationships would help those in need to cope effectively with their problems, manage upset and maintain a positive sense of self, that is, emotional support contributes to an individual's personal well-being.

Counselling is an important support service that may help people affected with HIV. Many previous studies examined on risk education counselling (Kanekar, 2011), safe sexual practices (Wolpow et al., 2014) and adherence counselling practices (Golin, 2004). In other words, those previous studies (Kanekar, 2011; Wolpow et al., 2014; Golin, Smith, & Reif, 2004), did not address experience of engaging in counselling session among people affected with HIV. However, a recent study by Christopoulous et al. (2013) showed that people affected with HIV discussed a lot of emotional stress and their needs for emotional support. Reflecting on the idea of Rogers (1961), the relationship between a counsellor and a client provides emotional support that helps the client to understand his or her own experience. In relation to this, Soon & Barnard (2000) confirmed that the experience of counselling assisted people affected with HIV by providing reassurance and comfort, as well as necessary information about the disease process, including lifestyle advice. The study also confirmed that people affected with HIV experienced limitations to their lives due to issues related to social stigmatisation. In addition to this, Zinck and Cutcliffe (2013) informed that counsellors could do a great deal to inspire and encourage maintenance of hope among people affected with HIV, especially facilitated self-acceptance as well as influenced them to confront their changed reality and make meaning of experience.

In light of the evidence that those affected with HIV often suffer from emotional disorders (Gordillo et al., 2009), requiring emotional support (Johnson & Pilcher, 2013) that can be provided by counselling (Rogers, 1961), this study will consider in what ways people affected with HIV experience emotional support during a counselling relationship.

3. Methodology

This study was performed using qualitative methodology. The main focus of this research was not to search for objective facts and objective truth, but the subjective experience captured in the individual stories of people affected with HIV. Qualitative methods allow the experiences of study participants to be interpreted and explained in the context of a specific environment (Denzin & Lincoln, 2000). A major feature of qualitative data is that they focus on the naturally occurring in a natural setting (Miles, Huberman & Saldana, 2014), generally disclosing or reflecting the language or words used in day-to-day life, and often incorporate words of the participants themselves to describe the psychological event, experience or phenomenon (Patton, 2002).

This study was conducted with people affected with HIV at a shelter home, which only housed this particular group. Ten subjects were selected based on purposive sampling to participate in this study, which are, living at this shelter home and regularly participating in counselling sessions. They are voluntarily living at this shelter home. This shelter home is community based project funded by non-governmental organization in the East Coast of Malaysia. Prior to the data gathering process, a list of names of those affected with HIV engaged in counselling sessions was obtained from the management office of this shelter home. The subjects were approached to participate, the research was explained and they were encouraged to participate in the study by the researchers. Sensitivity to the challenges and ethical issues of interacting face to face with the potential participants is crucial (Cresswell, 2012), which contributed to trust in relationship between researcher and participants. In total, ten participants volunteered to participate in this study.

The participants gave their informed consent prior to the data gathering stage. The process of obtaining informed consent explains the purpose of the study and assures the participants of the confidentiality of the information obtained during the study. According to Berg (2009), informed consent is about knowledge of something that has been agreed upon by the individual to participate in an event based on their choice, free from the elements of assault, threat or injustice or manipulation. Being open about the project or research will help develop a sense of trust between researcher and participants (Miles, Huberman, & Saldana, 2014). It is hoped that informed consent promotes an awareness of the participants of the confidentiality of the information as well as the experiences that have shared in this study.

The study involved a semi-structured interview, a non-participant observation and diary writing, with the

semi-structured interviews providing the main data of the study. Prior to the interview session, the researchers gave power to the participants to decide on the date, time and place for the interview as this research aims to understand their experiences, and being able to make such decisions may create feelings of readiness to share their experiences. In other words, from the beginning of their participation, they could feel their importance, and these feelings may promote their willingness to cooperate in the interview.

The interview protocols and questions were prepared prior to the actual data gathering, with preliminary interviews conducted first with non-research participants. These preliminary interviews were to gain experience in conducting interviews and facilitating the participants' stories. They also helped to define the interview style and how to handle the participants' accounts. Referring back to the actual data gathering process, each subject participated in two interviews conducted after their counselling sessions. The emphasis of a semi-structured interview is on meaning (Willing, 2008). In addition, the semi-structure interview is flexible to gather information, allowing the participants to describe their experiences in their own words and ways (Merriam, 1998). Therefore, the researcher is required to understand what is meant by interviewee without considering how they have chosen to say it in that particular way. The semi-structured interviews enabled the researchers to ask questions systematically, but the answers given by the participants had no limit and no special structure. Most of the questions were designed to allow the researchers to explore more about the personal experience of participants, revealing their thoughts and feelings (Patton, 2002). Each interview lasted between 45 minutes and one hour, including time for warming up, the interviewing phase and time for cooling down at the end of the interview.

The interview questions employed in this study are as follows:

First interview

1. What you would like to describe your background?
2. What you would like to describe your current situation?
3. What are your strengths?
4. What are your feelings after discovered you are HIV positive?
5. What you would to tell me your experience in counselling?
6. Tell me your interest in engaging in counselling.
7. How your experience of relationship with the counsellor?
8. What are activities that were conducted during counselling?
9. Explain about impact of those activities on yourself.

Second interview

1. Tell me about your expectations on counselling
2. What are you ideas on counselling?
3. What are changes that occur as a result of counselling?
4. Things that contribute to changes that mentioned.
5. Your satisfaction on the counselling that have been engaged.
6. Your feelings after have been through in counselling.

Observational data was also collected in this study. The purpose of observational data is to describe the setting that was observed, the activities that took place in that setting as well as the people who participated in those activities (Patton, 2002). The advantages of observation include the opportunity to record information as it occurs in a particular setting and to study actual behaviour (Cresswell, 2012). Observation is essential in gaining a holistic perspective of the individual because it captures the context in which people interact (Patton, 2002). In this study, a non-participant observation was performed, when the researcher visited the shelter and recorded notes without becoming involved in the activities of the participants (Cresswell, 2012). As a non-participant observer, the researcher took notes about behaviour as well as the verbal and non-verbal communication patterns of study participants. The observation was performed twice for each of the study participants. In addition, the researcher also observed and video recorded the study participants while engaged in their counselling sessions, in particular, their verbal and non-verbal communication patterns.

Participants were also required complete diary entries. According to Berg (2003), writing a diary refers to a

record of the thoughts, feelings, opinions or actions which allow comparison of self-reported information by study participants during an interview and what was written in the diary. The diary provides opportunities for the research participants to write experiences, actions and about themselves (Gavin, 2008). In this study, participants were required to write about their experiences as a person affected with HIV and engaging in counselling sessions. They were required to complete pre-prepared statements, which were open-ended to provide freedom for the participants to choose their words and style in writing their personal experience. Each participant was required to complete two diary entries during the study period.

The open-ended statements for diary writing were as follows:

1. After engaging in counselling session, my feelings are
2. During the counselling session, I am doing
3. My feelings during the activities
4. What I learn from this counselling session
5. My view on counselling services

4. Data Analysis

In this study, data were analyzed using thematic analysis. This method is not concerned with the overall topic of the text analysis, rather the identification of themes and sub-themes (Howitt & Cramer, 2008). In this study, researchers used data from the interview transcripts and diary entries that been prepared by study participants to identify significant themes. The stories of the participants were treated equally. The interview transcripts and diary entries were read repeatedly in order to obtain an overall picture of the participants' stories. Then, a significant statement relating to the experience of the participant was highlighted. This process, obtaining an overall picture of the participant's experience and extracting a significant statement, was performed with each of the participants' stories. Then, the researchers created a description of the significant themes identified and prepared a report based on the themes.

5. Findings

The stories of Amran, Wan, Jaafar, Kama, Faizur, Fadzil and Kimi (these are not their real names) are presented below.

Amran, aged 47, was a hardcore drug addict and he acquired HIV three years ago through sharing needles. He also had tuberculosis. Amran has attended counselling sessions for the past six months at the HIV shelter home.

Wan, aged 45, was a hardcore drug addict, becoming infected through sharing needles and has lived with HIV for nine years. He also had tuberculosis and has attended counselling sessions for the past seven months at the HIV shelter home.

Jaafar, aged 37, was a hardcore drug addict, acquiring HIV eight years ago through sharing needles. He also had hepatitis and has attended counselling sessions for the past three months at the HIV shelter home.

Kama, aged 35, was a hardcore drug addict and he acquired HIV infection by sharing needles. Kama also had tuberculosis. He has had HIV for five years and attended counselling sessions at the HIV shelter home for the past seven months.

Faizur, aged 37, was a hardcore drug addict and became HIV infected by sharing needles. He also had tuberculosis and has lived with HIV for thirteen years. He has attended counselling sessions at the HIV shelter home for the past year.

Fadzil, aged 44, was diagnosed with HIV from his sexual relationship ten years ago. He became stressed and depressed with his situation, turning to drug use. Fadzil also had tuberculosis and has attended counselling sessions at the HIV shelter home for the past three months.

Kimi, aged 41, was diagnosed with HIV from his sexual relationship eleven years ago. He was also a drug user and had tuberculosis. He has attended counselling sessions at the HIV shelter home for the past two months.

The findings showed that the participants' experience of engaging in counselling developed meaningful feelings and that their interaction with the counsellor contributed to these feelings. In addition, their acceptance of the counsellor during the interaction helped them to feel emotional support, which contributed to feeling that they had the strength to face up to challenges they encountered as well as feeling relieved to have an opportunity to tell other people about their struggles.

Emotional support

Emotional support is about the experience of care, empathy, love, respect and trust in a relationship (Burlinson, 2003). Counselling sessions provide an opportunity to people affected with HIV to share their experiences with another person, being a counsellor. The interaction with someone who is willing to listen as well as to understand them creates positive feelings, that is, engaging in counselling sessions contributes to emotional support. The research participants indicated that the counselling sessions provided opportunities to express their stories, which contributed to them feeling supported and understood. Their accounts also indicated that they felt motivated to face their daily life in a positive way. In addition, they also revealed that they experienced feelings of relief due to having the opportunity to share their experiences with the counsellor. The experiences as told by the research participants are outlined below.

i. Supported and Understood

The research participants indicated that the counselling sessions provided opportunities to express their stories, as well as to experience acceptance, which contributed to feelings of being supported. According to Amran, counselling helped him not to dwell on HIV. He considered the counselling session as the only place to express his feelings:

"I have no place to speak about myself. However, during counselling sessions I can express everything that I would like to. People in outside world could not accept me, someone affected with HIV. Everyone would be scared of my situation. I feel relief when I can share everything in the counselling sessions."

Amran also said that acceptance of the counsellor is vital to people affected with HIV and that this acceptance gave him emotional support:

"I am totally need support of other people. During my feeling of sad and at my low self, when there is someone come and show their their concern, I feel appreciated."

Another participant, Jaafar, said that acceptance of the counsellor also made him feel understood and he considered the counselling sessions as an ideal place to express his feelings. The acceptance provided him with emotional support:

"I chose to attend counselling sessions because it is the only place that I feel comfortable. The counsellor was really understood how I felt. I can say and express everything to the counsellor."

In addition, Jaafar's non-verbal behaviour during the non-participant observation was similar to his verbal behaviour. He appeared comfortable and confident participating in the counselling sessions. He showed his serious attention during sharing stories in the counselling sessions.

Kama also mentioned in his diary that the counselling session was a place to express his feelings. He felt that he was understood and supported during the counselling sessions:

"I feel very comfortable and confidence because I have someone who is willing to listen to my feelings. At that moment I felt the counsellor was really understood and gave support me."

The participants indicated the opportunities to tell their stories during the counselling sessions and that the acceptance of the counsellor contributed to their feelings of being understood and supported, which they could not receive from other people.

ii. Feeling Motivated

Being in a counselling relationship is also considered as a source of motivation for the research participants, particularly in facing struggles in daily life. Amran indicated that the counselling sessions provided him with encouragement and motivation:

"When I got depressed, everything was disturbed. I refused to take medicine. So by attending the counselling sessions it helped me to have courage and motivation. Engaging in counselling creates support for me."

Wan also stated that his experiences in the counselling sessions also motivated him and he considered the counselling sessions as a main priority:

"Now, I think that counselling is my first priority because it helped me a lot, especially to motivate myself. I feel more calm and no more stress after attending counselling sessions. Counselling is very important to me."

Faizur also considered the counselling as motivational. He said that the experience of engaging in counselling sessions contributed to his self-awareness about his life as someone with HIV:

"I am aware of my self and having some courage to continue my life. The counsellor understood how I felt. The

counsellor was very concerned towards my struggles. This is the reason that I still continue to attend counselling sessions. I think it is the best me."

In addition, Faizur's non-verbal behaviour was similar to his verbal expression. He looked comfortable in the counselling sessions, giving positive responses and engaging in the activities. He also stated in his diary that counselling contributed to his feelings of being understood, which promoted his motivation:

"The counsellor was really understood my situation, I am a bad person with HIV. When I mentioned about feeling of sad, the counsellor showed his care towards me. I can forget all the sadness through his encouragement."

Kama wrote in his diary about how the counselling sessions were a source of motivation to him. He said that the activity of life charts conducted during one of the counselling sessions made him realise that he needed to be more positive about life:

"I like the activity of life charts because it made me to see my self in the real situation. I am aware that my life has to be changed for the better from day to day. "

Kimi also mentioned the activities during the counselling sessions. For him, the drawing activity about his future life led him to aim for a better future:

"I prefer to do the activity of life chart during the counselling session because from that I can realise about myself. I know I have to change and become a better person."

The participants indicated that counselling was a source of motivation; they wanted to do better in their lives as a result of the counselling sessions. The encouragement of the counsellors gave them the strength to better their lives.

iii. Feelings of Relief

The participants reported that being in a counselling relationship generated feelings of relief. Amran wrote in his diary about feelings of relief as a result of the counselling sessions:

"I felt relieved during the counselling session. The counsellor can really understood my situation. It is so obvious that I can feel the difference when I share my story with the counsellor and an ordinary person. Counselling is better for me, especially to have someone to understand my feelings."

In addition, Amran's behaviour also indicated his calmness and confidence in sharing experiences in the counselling sessions.

Wan felt that his experience in the counselling sessions created feelings of relief, especially being with someone that was willing to listen to his story:

"I am wanted to attend counselling sessions because it gave me some strengths to continue my life as a person affected with HIV. I felt relief everytime I attend counselling, having someone to listen to me, it is really important to me. "

In addition, Wan was observed crying while sharing his story, however, he managed to smile at the end of the counselling session. In his diary, Wan also expressed his experiences in the counselling sessions:

"Now I felt stressful. I miss my family so much. Unfortunately I could not afford to go back home. I shared and expressed my feelings to the counsellor. I felt relief because there was still someone who is really can understand how I feel. I think the counsellor was really understood my self. I feel supported when I am facing difficulties."

Kama also said that counselling experiences helped him to eliminate the stress:

"I chose to attend counselling because it helps me in dealing with my feelings, a kind of support to my feelings. I feel strong to do changes in my life. I can forget all the pressures in my life. "

Observation of Kama showed him to be comfortable, giving positive responses in the counselling sessions and looking confident when telling his story.

Another participant, Fadzil, said that the counselling sessions provide an opportunity for him to express his feelings and he felt relief after doing that in the session:

"I still remembered that I shared a lot during the counselling session and then I feel relieved"

Fadzil also reported that he satisfied when he expressed his feelings and that he felt appreciated when the counsellor supported him:

"I expressed my feelings during the counselling sessions, and told the counsellor about myself. I felt that the counsellor could understand me. I am satisfying with counselling, I am happy because I received some moral supports from the counselling. It is not easy to get supports from others, but I get it through the counselling."

In addition, observation of Fadzil showed that he looked serious when sharing his story in the counselling session but that he appeared calm after the session. In his diary, Fadzil wrote about the support he received through the counselling sessions:

"I feel comfortable to share my feelings with the counsellor. The counsellor was really understood me. I can feel that there is a strength in me when I received supports from the counsellor. I am to thankful to the counsellor who is always understand me."

Another participant, Jaafar, wrote in his diary about how he felt calm when he received support during his sharing in the counselling sessions:

"I was so depressed when I am thinking about my children. However, I felt relief when I was accepted everytime I attended the counselling session. The counsellor was really understood and supported me. I think counselling is very important to me."

In summary, the people affected with HIV in this study reported that the experience of engaging in counselling provided them with the opportunity to share their experiences with the counsellor. Being with someone willing to listen to their stories promoted feelings of support, motivation and relief, that is, counselling provided the research participants with emotional support. Their stories indicated that they only experienced this emotional support when they engaged in the counselling session and with the counsellor. Experiencing the emotional support provided them with the strength to continue living.

6. Discussion

Being in a relationship with a counsellor provides an opportunity to encounter a meaningful experience. The results of this study indicate that people affected with HIV experienced feelings of being understood, supported and relieved while engaging in a relationship with the counsellor. In other words, the counselling sessions and the counsellors provided emotional support to people affected with HIV. Emotional support is a significant experience in the life of people affected with HIV; being able to experience emotional support helps them to view their lives in a more positive way.

The participants reported that their relationship with the counsellor provided them with opportunities to share their experiences, enabling them to deal with struggles and stress, contributing to feeling understood and supported. These findings are in accordance with Burleson's view (1984, 2003) that the support provided by close relationships would help those in need to cope effectively with their problems, manage upset, and maintain a positive sense of self. In addition, this study supports previous research by Soon & Barnard (2000) and Chritopoulous et al. (2013) of the impact of counselling on people affected with HIV. For example, Amran and Kama reported that they managed to deal with feelings of upset and to promote feelings of confidence as a result of this relationship. In addition, the findings of this study confirm that the relationship with others in helping individuals to understand themselves contributes to positive feelings about themselves (Rogers, 1951). Despite this, the research participants were living at a shelter home with limited access to significant family members, which might disturb their potential in creating positive feelings about themselves.

This study also indicated the way in which the emotional support helped people affected with HIV, for example, Wan managed to control his negative feelings. As a result of emotional support that he experienced in counseling sessions. Rogers (1961) said that individuals receive negative and positive attention at the same time, however, they are able to manage tension and stress despite the negative attention that they receive. With regard to Wan, despite his negative feelings, he was able to focus on his feelings of happiness, which is having someone to listen to his story. In addition to idea of attention, these findings further supported the study by Zinck & Cutcliffe (2013), which found that the qualities of counsellors that had promoted self-awareness among people affected with HIV, and those three qualities were counsellor's self-awareness, counsellor knowledge of HIV/AIDS as well as counsellor hope and expectancy. In other words, knowledge of HIV/AIDS would help a counsellor in creating an emotional support to people affected with HIV.

The participants also reported that the opportunity to share their experiences made them feel motivated to face up to their struggles and challenges. As discussed previously (Soon & Barnard, 2001; Gordillo et al., 2009), counselling helps people affected with HIV to feel strong about themselves. Indeed, Jaafar believed that counselling was an important experience in providing motivation as someone affected with HIV. Amran also mentioned that counselling is an important requirement for him, especially to help him realise his responsibilities.

Moreover, Faizur reported that counselling made him aware of his responsibility towards himself, as a person affected with HIV. The impact of the emotional support provided by counselling motivated those affected with HIV and increased their awareness of their responsibilities.

Previous research has discussed the negative experiences of people affected with HIV (Gordillo et al., 2009; Marks, 2008; Pursell, Fanner, & Barnes, 2013). In relation to this, Okwun and Siraj (2010) mentioned that the main goal of counselling sessions must be focused on the emotions of clients affected with HIV. With regard to this study, the participants reported feelings of relief as a result of having someone willing to listen to them, that is, they experienced emotional support. People with HIV often experience anger, fear, as well as self-denial (Gordillo et al., 2009; Marks, 2005; Pursell, Fanner, & Barnes, 2013; Haslee Shahril, 2007), which may be related to being unable to share their daily struggles and challenges. Being able to share and tell the counsellor their stories generated feelings of relief, for example, Kama stated that counselling helped him deal with his stress. However, prior to engagement in counselling, the research participants believed that they needed to keep their stories to themselves as no one would want to listen to them. As highlighted by Rogers (1961), individuals can only understand themselves better when they are in relationship with other people. With regard to the research participants, they managed to understand their experiences and accept their responsibility with help of the counsellor during the counselling sessions. The counsellor, by being accepting, non-judgmental and genuine, helps those with HIV to feel comfortable to engage in counselling, ultimately allowing them to have meaningful experiences (Rogers, 1951). In addition, counsellor's self-awareness, counsellor knowledge of HIV/AIDS as well as counsellor hope and expectancy (Zinck & Cutcliffe, 2013) would help in promoting positive daily lives.

7. Conclusion

The emotional support provided by engagement in counselling sessions is an important experience for people affected with HIV. The opportunity to share their experiences with someone willing to listen created feelings of support, being understood, motivation and relief, which had a positive impact on their daily struggle living with HIV. Therefore, counselling session that easily access to people affected with HIV is very important in helping them to discover new possibilities in life.

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